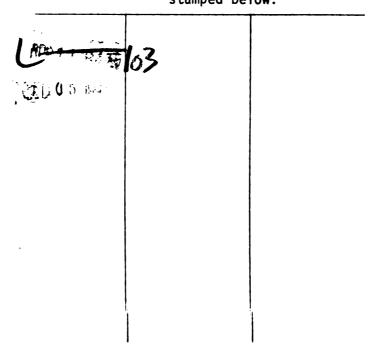


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# THE RELATIONSHIP BETWEEN PERCEIVED FAMILY FUNCTIONING AND PERCEIVED COMPLIANCE BEHAVIOR OF THE AMBULATORY ADULT ONSET DIABETIC

Ву

Barbara Bye Sipes

# A THESIS

Submitted to
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#### ABSTRACT

# THE RELATIONSHIP BETWEEN PERCEIVED FAMILY FUNCTIONING AND PERCEIVED COMPLIANCE BEHAVIOR OF THE AMBULATORY ADULT ONSET DIABETIC

By

# Barbara Bye Sipes

A descriptive study of 25 adult onset diabetics was undertaken to determine the relationship between the patient's perceived family functioning and her/his perceived compliance with selected aspects of the therapeutic regimen. The data were gathered by means of a questionnaire with two parts that was completed by the patient. The questionnaire was given one time only to each subject and was administered by the researcher to the first 25 adult onset diabetic patients who were between the ages of 30 to 70, lived with at least one other person, and were being treated by one of four private physicians.

The data were analyzed by using Peason Product-Moment correlation coefficient. The findings revealed no significant relationship at the .05 between perceived family functioning and perceived compliance behavior of the ambulatory adult onset diabetic. However, the nurse should continue to investigate influence of family functioning on the health state of diabetic as well as investigate barriers to compliance.

To My Husband

Gary

and

Children

Dan, Susan, Laura, and Linda

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#### CHAPTER I

#### THE PROBLEM

#### Introduction

The management of a chronic illness by a patient may require that he/she will have to acquire new behaviors in order to live with the illness. This new behavior we call compliance behavior since the patient must comply with a suggested health regimen. Reviews of literature that relate to compliance behavior in all illness regimens reveal that at least one- third of all patients do not comply with their therapeutic regimen (Haynes et al., 1979; Blackwell, 1973). In view of this lack of success, compliance currently may be one of the greatest therapeutic challenges facing the health professions (Gillum & Barsky, 1974).

The most recent and fairly complete review of literature on compliance behavior, conducted by Haynes and associates in 1979, suggests that research into the arena of compliance has focused on five main areas. These include: (1) demographic features of the patient such as age, sex, education, socioeconomic status, income, marital race, religion; (2) characteristics of the disease such as diagnosis, severity, duration, degree of disability; characteristics of the therapeutic regimen such as complexity, duration, type of regimen; (4) psychosocial

features of the patient such as health beliefs and knowledge of the disease and regimen; and (5) doctor-patient relationships.

The studies that were reviewed have provided some useful data. For example, we know that characteristics of the regimen have an effect on compliance behavior (Haynes et al., 1979). That is, noncompliance occurs most often when the regimen is long in duration, complex, and requires extensive behaviorial changes. Thus, since each of these characteristics is a feature of the treatment program for the chronic illness adult onset diabetes, it seems reasonable to assume that compliance may be a problem for the adult onset diabetic.

Few studies, however, have focused on the compliance behavior of the adult onset diabetics. The few studies that have focused on the compliance of the diabetic have investigated the effects of such variables as knowledge of the disease and therapeutic regimen (Bowen et al., Tagliacozzo et al., 1974; Watkins et al., 1967; Williams et al., 1967), doctor-patient communication (Hulka et al., 1975), and health-beliefs (Cerkoney & Hart, 1980). This past research has provided some useful information. However, few studies have investigated the effects of the family variable on the diabetic's compliance behavior, i.e., the influence of the adult onset diabetic's family on the patient's adherence to a therapeutic regimen. Neglect of

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this subject is unfortunate since chronic illness usually has an effect on the individual's family as well as the patient (Rakel, 1977; Barsky, 1976). Moreover, the manner in which a family responds to the illness can have a marked effect on the course of that illness as suggested by Rakel (1977).

Some studies do exist that investigated the family's influence on compliance behavior in chronic illness. The findings of such studies show that there is a positive relationship between family influence and compliance behavior. However, these studies were not of diabetes but rather of arthritis (Oakes, 1970; Ferguson & Boles, 1979), hypertension (Caplan et al., 1976), orthopedic disability (Litman, 1966), and kidney disease (Steidl et al., 1980). Moreover, most of these studies focused mainly on family support related to adherence to a regimen.

It is reasonable to expect that family support may be influenced by the overall functioning of the family. Yet, the writer found only one study that examined the relationship of family functioning to compliance behavior. This study was conducted by Steidl and associates (1980) who found that there was no significant relationship between total family functioning as perceived by family therapists and compliance behavior in kidney dialysis patients. However, Steidl and associates' study (1980) did not investigate the family functioning as perceived by the

individual within the family. Since an individual's perception may influence her/his behavior the individual's perception of her/his family functioning may influence her/his adherence to a therapeutic regimen. There are some studies (Pless & Satterwhite, 1973; Smilkstein, 1978) that have examined the question of the evaluation of perceived family functioning in relation to health care in general but not specifically in relation to compliance behavior.

In summary, it is apparent that many studies have been completed on compliance behavior in chronic illness and a few studies have considered the influence of family Some studies support on compliance behavior. have been completed that deal with compliance behavior in adult onset diabetes. However, there have been no studies located that have investigated the relationship between perceived family functioning and perceived compliance behavior in the adult onset diabetic. The investigator believes that this is a significant deficit in compliance research since she believes that the way in which a family interacts may have an effect on compliance behavior.

For example, if the relationships among family members are positive, it might be expected that significant others would provide support that might motivate increased compliance such as encouragement, validation of self-image, and/or reminders. By contrast, if such psychological and/or functional support was lacking, one might expect that a

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person would be less motivated to comply. Social support such as the example just given are reflected in the concept of family functioning. Thus, it would seem beneficial to investigate the relationship between family functioning and compliance behavior.

involved Therefore, because nurses are with teaching, support, and compliance behavior of ambulatory patients, the nurse should investigate the impact of family functioning on compliance behavior. This is so because the goal of nurses in the expanded role is to help patients reach their maximum potential for daily living and reaching this maximum potential, when an individual has a chronic illness, often depends on compliance with a therapeutic regimen. An analysis of information gained from a study of family functioning and perceived perceived compliance behavior could be useful to nurses in practice, education, and research.

#### Purpose

The purpose of this study is to investigate the relationship between the perceived family functioning and the perceived compliance with selected aspects of the prescribed therapeutic regimen of a sample of ambulatory adult onset diabetics.

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#### Statement of the Problem

Is there a relationship between the perceived family functioning and the perceived compliance with selected aspects of the prescribed therapeutic regimen of ambulatory adult onset diabetic patients?

# Statement of the Hypothesis

There is a relationship between the perceived family functioning and perceived compliance with selected aspects of the prescribed therapeutic regimen of ambulatory adult onset diabetic patients.

#### Subresearch Ouestions

- 1. How does the ambulatory adult onset diabetic perceive her/his family functioning?
- 2. How does the ambulatory adult onset diabetic perceive her/his compliance with the therapeutic regimen?

#### Definition of Concepts

In this section the concepts that will be defined are (1) adult onset diabetes, (2) ambulatory care, (3) the therapeutic regimen, (4) perceived compliance behavior, and (5) perceived family functioning.

### Adult Onset Diabetes

Diabetes is a disorder of carbohydrate, protein, and fat metabolism and is classically characterized by hyperglycemia and glycosuria (Skillman & Tzagournis, 1977). There are two types of diabetes, adult onset diabetes and juvenile onset diabetes. Ninety percent of those with the

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disease have adult onset diabetes (Cohen & Etzwiler, 1976). Since adult onset diabetes is the most prevalent type of diabetes, subjects with adult onset diabetes, age 31 to 70, will be selected for this study.

Adult onset diabetics have the following characteristics: (1) are diagnosed after age 30, (2) have a gradual onset of the disease, (3) are not usually insulin dependent, and (4) are usually overweight (Cohen & Etzwiler, 1976). Adult onset diabetics are less prone to develop acute complications such as acidosis and coma, but do tend to develop chronic complications. These chronic complications are due to the fact that diabetics tend to develop arteriosclerosis at an earlier age than nondiabetics (Guthrie & Guthrie, 1977). And, arteriosclerosis frequently results in the development of other chronic vascular disease such as coronary artery disease and peripheral vascular disease.

The criteria to be used for the selection of the subjects who will participate in this study will be discussed in more detail in Chapter 4.

# Ambulatory

Ambulatory is defined as not confined to bed, to hospital, or to home. Adult onset diabetics who are confined to bed at home or confined to a health care facility will be excluded from this study. Being confined to bed or a health care facility usually results in care

being administered by someone else. This study is concerned with adult onset diabetics who are responsible for their own care. However, although subjects will not be under the direct supervision of a health care provider, they will be receiving follow-up care for their diabetes at a minimum of two times per year in an ambulatory care setting.

#### Therapeutic Regimen

The therapeutic regimen is the clinical recommendation prescribed by the health care provider for diabetes management. Certain aspects of the regimen are common to many adult onset diabetics. For example, diet, medication, and follow-up appointments are usually given as written prescriptions by the health care provider. Therefore, these will be the dimensions of the therapeutic regimen that will be considered for this study.

First of all, most basic to all diabetic regimens is a calculated diabetic diet. If no attention is paid to the diabetic patient's food intake it is impossible to keep blood sugar levels within prescribed limits (Cohen & Etzwiler, 1976). For this study, the aspect concerning the diet will include adherence to general principles such as eating the recommended foods in the recommended amounts at the appropriate times.

In addition to a prescribed diet, the diabetic may be on an oral hypoglycemic or a small dose of insulin (less than 60 units per day). The aspects considered for this

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study concerning medication will be taking insulin or oral hypoglycemics in the prescribed doses, at the prescribed times, and watching for side effects.

Finally, most adult onset diabetics need to be seen by their health care provider at two to three month intervals for continued management, although the frequency of follow-up appointments may vary with the patient, the nature of the disease, and the physician (Cohen & Etzwiler, 1976). Aspects of the follow-up appointments for this study include keeping well and ill follow-up appointments and laboratory appointments for the assessment of blood sugar.

Exercise, urine testing, and general hygiene including special foot care also are important aspects of diabetic care. These latter dimensions, however, are not usually given as written prescriptions, but are often based on verbal instruction of the health care provider. This information given per verbal instruction is not always emphasized equally in all settings and to all types of diabetics (insulin dependent as well non-insulin as dependent). Compliance with exercise, urine testing, and general hygiene may be indicated by the patient as poor when in fact the information in these areas may not have been emphasized and the patient may not perceive them as being Therefore exercise, urine testing, and general hygiene will not be measured as dimensions of compliance this study.

# Perceived Compliance Behavior

Compliance is defined as the extent to which a patient's behavior (in terms of, for example, taking medication or following a diet) coincides with medical or health advice (Haynes et al., 1979). Perceived compliance behavior indicates the patient's image of reality concerning her/his adherence to the prescribed regimen. This study will ascertain the patient's image of reality concerning the extent to which he/she follows her/his diet, takes medication, and keeps follow-up appointments as prescribed by her/his physician.

compliance A one time measurement of perceived behavior will be used. Due to insufficient objective parameters to measure compliance behavior with the diabetic regimen from a one time measurement (Bondy & Felig, 1971; Leslie et al., 1979; Tattersal et al., 1980), compliance will be based on the patient's report of how the clinical prescriptions of the health care provider are implemented. According to Haynes and associates (1979) self-reporting compliance behavior can be as effective a means of measuring compliance as more objective means. A study by Green and colleagues (1979) substantiates the effectiveness of selfreport. By contrast, Ferguson & Boles (1979) found that tend to over-estimate compliance behavior. if patient Nevertheless, in this study, even а over-estimates her/his compliance behavior it would not

negate the fact that a relationship may exist between perceived family functioning and perceived compliance behavior.

Although a one time of measurement objective clinical parameters, such as weight and blood sugar, are not sufficient to measure compliance behavior, weight and blood sugar will be collected to substantiate the effectiveness of self-report. For example, weight maintenance or weight loss gives an estimate of compliance with the diabetic diet and blood sugar levels give an estimate of diabetic control. However, it is realized that blood sugar levels are influenced by several things such as stress, exercise, infection, in addition prescribed diet to the medication. Nevertheless, the presence of blood sugar levels within normal limits will add veracity to the compliance behavior concerning diet self-reported and medications. The parameters used to estimate diabetic control will be discussed in more detail in Chapter 4.

# Perceived Family Functioning

Smilkstein (1978) defines family functioning as that behavior which promotes emotional and physical growth and maturation of all members. Perceived family functioning indicates the patient's image of reality concerning the way in which her/his family functions. Family is defined by Smilkstein as a group consisting of the patient and one or more persons, children or adults, in which there is a

commitment for members to nurture each other. This definition is encompassing enough to include a wide range of family types including the traditional nuclear family and families more broadly defined.

Smilkstein (1978) established parameters by which a family's functioning could be measured by devising five basic components of family functioning which he called the Family APGAR. The components are defined as follows:

Adaptation: Adaptation is the utilization of intra

and extra- familial resources for problem solving when family equilibrium is

stressed during a crisis.

Partnership: Partnership is the sharing of decision

making and nurturing responsibilities by

family members.

Growth: Growth is the physical and emotional

maturation and self-fulfillment that is achieved by family members through mutual

support and guidance.

Affection: Affection is the caring or loving

relationship that exists among family

members.

Resolve: Resolve is the commitment to devote time

to other members of the family for physical and emotional nurturing. It also usually involves a decision to share

wealth and space.

Smilkstein (1978) developed this family function paradigm believing each of these components has a unique function while still being interrelated to overall family functioning.

Family functioning usually is a subjective measurement and is based on an individual's perception, that

is, her/his image of reality (King, 1971). Studies by Haggerty (1965) and Geismar (1962) have shown that internal functions within a family are not easily observable by outsiders and it is difficult to obtain agreement between observers. A more recent study, by Good and her colleagues (1979), seems to substantiate this finding. That is, Good and her colleagues (1979) found only a moderate agreement (r = .64) between the patient's perception of her/his family functioning as indicated by the Family APGAR index score and how the therapists perceived the individual's functioning. Therefore, since the way in which the individual perceives an event or situation is her/his of reality and is usually the basis for her/his behavior, this study is concerned with how the diabetic patient perceives her/his family functioning rather than how the individual's family functioning is perceived by others.

#### Descriptive Data

Research has shown that demographic variables are not predictive of compliance behavior (Haynes et al., 1979; Marston et al., 1970). Therefore, the demographic variables in this study will be used only for descriptive purposes. The demographic data that will be utilized for this study are: age, sex, race, income, and marital status. Since this study is concerned with family functioning, the size and composition of the household of the participants will also be determined, i.e., the number, age, sex, and

relationship of people with whom the subject lives.

# Confounding Variables

The confounding variables that will be investigated in this study are: (1) the number of years the patient has been a diabetic; (2) the number of chronic illnesses the patient has in addition to diabetes; (3) the complexity of the patient's regimen; and (4) whether the patient has been hospitalized for diabetes within the last six months.

According to Haynes and his colleagues' (1979) review of the literature, there is no association between the number of years the patient has had a disease and compliance. By contrast, there is an inverse relationship between duration of the regimen and compliance behavior. That is, the longer an individual is on a regimen, the less likely he/she is to comply. Since the diet is basic to all diabetic regimens it is assumed that patients would have been on a diabetic diet for the length of their illness. This is so because the first treatment prescribed to control diabetes is diet. Therefore, data concerning the number of years with diabetes will be used as an indirect measure of duration of treatment.

Reasearch (Haynes et al., 1979) has shown that the complexity of the regimen influences compliance behavior, i.e., more complex regimens are inversely related to compliance behavior. The presence of chronic illnesses other than diabetes would serve to make the therapeutic

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Still another confounding variable to be included is the evidence of hospitalization within the last six months for diabetes. Hospitalization for diabetes may result in reinforcement teaching for diabetes. Research has shown that the patient's knowledge of the disease or regimen is not consistently associated with compliance behavior (Haynes et al., 1979). Yet, it seems reasonable to assume that the recent reinforcement teaching may serve temporarily to improve perceived compliance behavior.

In summary, the purpose of this study is to ascertain the relationship between perceived family functioning and perceived compliance behavior. However, since research has shown that other variables appear to influence compliance behavior as well, data will be collected concerning the following confounding variables:

(1) the number of years the patient has had diabetes; (2) the number of chronic illnesses other than diabetes the patient may have; (3) the complexity of the patient's regimen; and (4) whether or not the patient has been hospitatlized within the last six months for her/his diabetes. An analysis will be made to determine if these confounding variables with are correlated perceived compliance behavior. In addition, the data for confounding variables will be used for descriptive purposes concerning the subject's diabetes.

## Limitations

The limitations of the study are;

- 1. Patients with adult onset diabetes who have various other chronic illnesses and a more complex regimen may respond to questions differently than those who only have adult onset diabetes.
- 2. This study does not control for other variables also believed to influence compliance such as the doctor-patient relationship, and health beliefs, e.g., perceived susceptibility and the perceived severity of the disease, or the costs and benefits of following the therapeutic regimen.
- 3. The subjects in this study have not been controlled for severity of diabetes.
- 4. The varied lifestyles of the patients involved may influence how they perceive compliance and family

- functioning.
- 5. The patient's perceived view of family functioning may be variable and there may be a slight change from day to day. A crisis may temporarily alter the patient's perceived family functioning to a great degree.
- 6. The subjects who agree to participtate in the study may be different from those who refuse.
- 7. The sample size is small, a convenience sample from limited geographic areas and limited settings, and therefore not generalizable to the larger population.
- 8. A rare case of juvenile onset diabetes has its onset after the age of 30 and may inadvertently be included in this study.
- 9. The age range for adult onset diabetes extends across several developmental stages of the life cycle. A consideration of way in which developmental stages influence response to the family functioning section of the questionnaire is not included in this study.
- 10. Both family functioning and compliance behavior are measured subjectively and an individual who is positive about one variable (e.g., family functioning) may tend to be positive about the other (e.g., compliance behavior).
- 11. The instrument was developed by the researcher and has not been tested for validity or reliability.

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## Assumptions

In this study the researcher is making the following assumptions:

- It is assumed that perceived family functioning can be measured.
- 2. It is assumed that measurement of "perceived" compliance behavior is an accurate and reliable method of measuring compliance in the diabetic patient.
- 3. It is assumed that patients' perceived family functioning and perceived compliance behavior can be adequately measured by means of the questionnaire.
- 4. It is assumed that the family functioning instrument and the compliance instrument will be sensitive enough to indicate level of perceived family functioning and level of perceived compliance behavior.
- 5. It is assumed that the patient's answers to the questions on the instrument reflect her/his true perceived compliance behavior and perceived family functioning.
- 6. It is assumed that the age group selected is typical of adult onset diabetics.
- 7. It is assumed that the family functioning section of the questionnaire will be applicable to all the developmental stages of the life cycle that adult onset diabetes crosses.

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# Overview of Study

The study is presented in six chapters. In Chapter introduction to the problem, purpose of the study, statement of the problem, definition of concepts, statement of the hypothesis, and limitations and assumptions of the study are presented. Chapter II contains the conceptual framework and focuses on family functioning and compliance behavior in chronic illness as well as how each of these concepts relates to nursing. Literature that focuses on compliance, chronic illness, diabetes, family functioning, and the family's influence on compliance is reviewed in Chapter III. In Chapter IV the method used to collect data, the research design, operational definitions, population, sample, and source of subjects are described. In Chapter V the data are presented and discussed. The summary, conclusion. implications for nursing, and the recommendations for additional research are presented in Chapter VI.

#### CHAPTER II

#### CONCEPTUAL FRAMEWORK

### Introduction

Health is a dynamic state in the life cycle of an individual. According to King (1971), this dynamism implies continuous adaptation to stresses in the internal and external environment through optimum use of one's resources to achieve maximum potential for daily living. Health may be viewed as a continuum with wellness and illness as the end points. At any point on this continuum the individual has positive attributes of wellness simultaneously with negative attributes of illness. The balance of these well and ill attributes determines the individual's state of health. The highest level of wellness is the maximum level of functioning of a person at any specified time and place. The ultimate aim of nursing is to enable individuals to reach their highest level of wellness.

Illness is the inability of the individual to meet her/his needs in a way that will allow her/him to achieve maximum potential for daily living. Illness is a stressor to the individual's internal and external environment which requires adaptation. When the illness is acute, only a temporary adjustment need be made. For example, there may be a need to alter the diet, to take medication, and/or to

limit activities for a brief period of time. In addition, there may be a temporary strain on financial resources. contrast, when the disease is chronic, it may be necessary to make permanent adjustments. That is, there may be a permanent need to restrict activities, to change diet, to take medications for an indefinite period, or to adjust to an indefinite strain on financial resources. These adjustments are permanent because in most cases the chronically ill individual is not expected to recover. Moreover, to avoid the complications of the disease lead as normal a life as possible, the individual expected to comply with the therapeutic regimen throughout her/his lifetime to maintain her/his maximum potential for daily living.

The effects of any chronic illness are not limited to the patient alone, however. Most individuals live within a family unit. According to Rakel (1977), illness in one family member affects all other family members and recovery from illness is likewise hampered or facilitated by the relationships within the family. In other words, in chronic illness, the ability of a patient to reach her/his maximum potential for daily living may be hampered or facilitated by the interaction of family members, i.e., the functioning of the family.

In short, in chronic illness, the interaction of the members within the family, i.e., family functioning, appears

to contribute to a patient reaching her/his maximum potential for daily living. Moreover, in chronic illness, compliance behavior appears to contribute to a patient her/his maximum potential for daily reaching Therefore, it is reasonable to expect that there may be a relationship between family functioning and compliance behavior in chronic illness. Furthermore, since individual's image of reality is reflected in her/his perception (King, 1971), it also is reasonable to expect that there may be a relationship between perceived family functioning and perceived compliance behavior. Finally, since the ultimate aim of nursing is to help the patient reach her/his maximum potential for daily living, insights derived from research into the relationship between perceived family functioning and perceived compliance behavior in chronic illness can be of value to nursing practice and education.

Accordingly, the conceptual framework for this study is based on these two concepts, i.e., perceived family functioning and perceived compliance behavior in chronic illness. These concepts are discussed in more detail in subsequent sections as is their relationship to nursing and the nursing theory, based on King (1971), which is used in this study.

# Compliance Behavior in Persons with Chronic Illness

Compliance is defined as the extent to which a patient's behavior coincides with medical or health advice (Haynes et al., 1979). Studies have shown that compliance with all therapeutic regimens is disturbingly inadequate and that approximately one-third of all patients do not adhere to therapeutic regimens (Blackwell, 1973; Marston, 1970; Davis, 1966). Furthermore, research has shown that compliance behavior is reduced even more when the regimen is long in duration, complex, and requires extensive behavioral changes (Haynes et al., 1979).

Diabetes is an example of a chronic illness in which compliance behavior presents difficult and challenging problems for patients. This is so because control of diabetes involves extensive behavioral change and a complex regimen throughout the patients lifetime. For example, the therapeutic regimen for diabetes involves dietary alteration, taking daily medications, urine testing, alteration in exercise, special attention to hygiene and foot care, and frequent follow-up appointments. Moreover, the regimen for diabetes is complex. For example, the patient must not only understand and follow the prescribed diet but he/she also must eat the food in specified amounts Furthermore, the specified times. patient coordinate the amount of activity he/she engages in with the food eaten and medication taken. Finally, since many

diabetics frequently have other chronic illnesses such as cardiovascular diseases (Guthrie & Guthrie, 1977), they also must take medications for these diseases, further increasing the complexity of their regimen.

Compliance behavior, however, presents difficult and challenging problems for the health care provider as well. For example, since most diabetic patients are treated in an ambulatory care setting, the patient is expected participate in diabetic control through compliance with a therapeutic regimen. But, the health care provider has little ability to enforce compliance behavior, e.g., he/she cannot ensure that a patient comply with the diabetic diet as directed, as would be the case in an institutional setting. In addition, there is no ideal way for the health care provider to detect whether or not the patient is complying. Therefore, it is difficult to know if a lack of improvement is due to noncompliance, an inadequate treatment plan or other factors. For example, variables such as infection, stress, and exercise, can influence blood sugar levels and affect diabetic control (Guthrie & Guthrie, 1977). Moreover, clinical outcomes, such as blood sugar and urine glucose levels give only a fragmentary glimpse of diabetic control (Bondy & Felig, 1971). As a result, a laboratory result from one point in time may be reflective of these other factors rather than lack of compliance behavior. At the same time, reliance on self-reports of

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compliance frequently used by physicians, also may be an inadequate measure of patient behavior. This is so because patients may overestimate their compliance behavior.

Evaluating compliance, therefore, is a problem for Evaluation of compliance behavior, however, the provider. also may be a problem for the researcher because it is difficult to find a reliable means to measure compliance behavior from a one time measure. Yet. studies hypertensive patient have shown a relationship between self-reported compliance with taking antihypertensive medication and blood pressure control (Green et al., 1979; Hershey et al., 1980). Therefore, even if study subjects do overestimate their compliance behavior, there may be a relationship between perceived compliance behavior and actual compliance behavior in the adult onset diabetic patient.

Perhaps because compliance behavior is such problem, much research has been conducted to explore its sources. Several of the potential variables that have been extensively investigated are: (1)demographic characteristics; (2) doctor-patient relationships; (3) characteristics such as health patient beliefs and knowledge; (4) disease features; and (5) features of the regimen.

Demographic variables (e.g., age, sex, education, socioeconomic status, income, occupation, marital status,

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race, and religion) have been studied most extensively because they are easy to identify and measure. Although demographic variables are easy to identify and measure they are relatively enduring. That is, even if a consistent relationship could be found between one or more of these variables and compliance behavior, in most instances little could be done to alter the situation. However, research has found that demographic characteristics are not predictive of compliance when examined apart from other variables (Haynes et al., 1979; Marston, 1970). Demographic variables, however, are valuable for descriptive purposes to depict the population represented in the study.

The doctor-patient relationship also has been studied and it has been found that indeed the patient's degree of satisfaction with the health care provider and the clinic has shown to be correlated with compliance (Becker, 1979). Nevertheless, since the investigation of doctor-patient relationships is a study in itself, variable will not be included in this study in an effort to narrow its scope. The exclusion of doctor-patient relationships as a variable will be considered a limitation to this study.

Still another variable that has been studied extensively as a potential predictor of compliance is the health beliefs of patients. Health beliefs include the patients' (1) perceived susceptibility to the disease and

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its complications; (2) perceived severity of the disease; and (3) perceived barriers to following the treatment regimen such as physical, psychological, and/or financial costs related to the therapeutic regimen. Studies of mothers of children with acute illnesses have produced data that show a positive association between compliance behavior and health beliefs (Becker et al., 1972; Charney et al., 1967; Francis et al., 1969). However, conflicting data has been produced regarding the health beliefs of adults with chronic illness (Green et al., 1979; Taylor, 1979; Cerkoney & Hart, 1980). Thus, even though health beliefs may influence compliance behavior it is apparent that other factors influence compliance as well. Accordingly, in an effort to limit the scope of this study, health beliefs will The lack of control for not be included as a variable. health beliefs will be considered a limitation to this study.

Knowledge also frequently has been examined to determine if it influences compliance behavior. The research conducted, however, has produced conflicting data. That is, some studies have shown no association between knowledge and compliance (Becker et al., 1974; Bille, 1977; Blackburn, 1977; Donabedian & Rosenfeld, 1964; Vincent, 1971) and others have shown a positive relationship between knowledge and compliance (Heinzelmann, 1962; Tagliacozzo & Ima, 1979; Watkins et al., 1967). Although knowledge of

diabetes or the regimen will not be investigated in this study, hospitalization for diabetes may be a confounding variable in this study. This is so because when a patient is hospitalized due to uncontrolled diabetes it may be secondary to noncompliance or it may be due to infection, illness, or severe stress. Nevertheless, regardless of the cause, patients who are hospitalized for uncontrolled diabetes usually receive reinforcement teaching. And, this reinforcement teaching may serve to improve their compliance temporarily. Therefore, hospitalization for diabetes may be a confounding variable in this study.

Yet another variable that has been thought to be potential predictor of compliance behavior and studied is features of the disease such as diagnosis, severity of the disease, and degree of disability. For example, Hulka and her colleagues (1975), in a study patients of Congestive heart failure and adult onset diabetes, found no relationship between disease features and compliance behavior. Similarly, Diamond (1968), in a study orthopedic and neurological problems, found no relationship between diagnosis or severity and compliance. In contrast, Donabedian and Rosenfeld (1964) in a study of chronically ill patients showed that the more severe the disability the more compliant the patients were. Thus, the relationship of features of disease to compliance behavior remains in question.

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Finally, features of the treatment regimen frequently also has been examined to determine if they are related to patient compliance behavior. And, Havnes and associates (1979), following an extensive review of the literature, indicated that a relationship does exist between features of the regimen and compliance behavior. That compliance with a therapeutic regimen is reduced when the treatment program involves extensive behavioral changes, more complex, and is continued over time (Haynes et al., 1979). It might be expected, then, that the features of the treatment regimen for diabetic patients would be related to their compliance behavior. Thus, since diabetes is the chronic illness being investigated in this study, features of the regimen such as duration and complexity may be confounding variables in the study.

To summarize, approximately one-third all of patients on therapeutic regimens do not Furthermore, compliance behavior is more difficult when the regimen is long in duration, complex, and requires extensive behavioral changes. The above features of a therapeutic chronic regimen are characteristic of most illnesses, Therefore, it is reasonable including adult onset diabetes. to expect the compliance behavior in adult onset diabetes may be a difficult and challenging problem.

Compliance behavior of the adult onset diabetic is challenging in that compliance affects control of diabetes,

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compliance affects control of diabetes, ability of patient to reach her/his maximum potential for daily living. Compliance for the patient is difficult because in diabetes the therapeutic regimen is complex, requires extensive behavioral changes, and is extended throughout the patient's Since it is difficult to detect noncompliance, lifetime. compliance behavior of the patient presents a problem for the health care provider as well. That is, it is difficult to assess the efficacy of the treatment plan since he/she cannot know whether a lack of improvement is due to an inadequate treatment plan or a lack of compliance. However, it has been reported that simply asking the patient in a nonthreatening manner is as effective approach as more objective means to detect noncompliance (Haynes 1980).

Because compliance presents problems for both the patient and health care provider, many variables have been investigated to ascertain their influence on compliance behavior. Some of these variables have been shown to influence adherence to a regimen and will be investigated in this study since they may act as confounding variables. For example, since duration and complexity of the regimen influence compliance behavior and since adult onset diabetics tend to develop other chronic illnesses, further increasing the complexity of the therapeutic regimen, it is reasonable to expect that the number of chronic illnesses

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other then diabetes and the complexity and duration of the regimen may be confounding to this study. Similarly, since of the disease and therapeutic regimen may influence compliance behavior, and since hospitalization for diabetes may lead to reinforcement teaching concerning diabetes and temporarily influence compliance behavior, hospitalization for diabetes in the last six months may also be confounding to this study. Health beliefs doctor-patient relationship also appear to influence compliance behavior. However, in an effort to limit the of this study, these variables will not be investigated, but instead, the lack of inclusion will considered a limitation of this study.

Demographic variables also will be included in this study even though it has been suggested that they do not appear to influence compliance behavior when viewed separately. Nevertheless, in this study demographic data will be used only for descriptive purposes since they are useful to depict the sample studied.

Another variable that appears to inluence compliance behavior of patient with chronic illness is the provision of support from family members (Caplan et al., 1976; Haynes et al., 1979). From research concerning the family's influence on compliance behavior (Heinzelmann & Bagley, 1970; Litman, 1966; Oakes et al., 1970; West et al., 1977) there is evidence that the way in which a family functions affects

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the patient's compliance behavior. In the next section family functioning and the family's influence on compliance behavior will be considered.

# Family Functioning and Family's Influence on Compliance Behavior

Most individuals live within a unit. This family unit may be a traditional or extended family, or it may be one of several other modern forms of the family more loosely defined. That is, to be considered a family, the unit need only include one or more persons, children or adults, who are committed to nurture each other (Smilkstein, 1978). Within such a family, relationships exist among members and each individual in the family affects all other individuals within the family (Rakel, 1977). Thus, when an individual has a chronic illness, the effects of the illness may not be limited to the patient alone. That is, illness in one family member may affect all other family members. Similarly, when a person has a chronic illness, her/his adjustment to the disease and its treatment also may be hampered or faciliated by the relationships within the family (Rakel, 1977). That is, positive family relationships may lead to positive self image which may lead to a desire to comply with the therapeutic regimen to attain or maintain health.

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members may be referred to as family functioning. The concept, although frequently referred to, is variably For example, Rakel (1977), equates family defined. relationships or interaction of family members with functioning. That is, according to Rakel (1977), families in which members exhibit love, discipline, tolerance, adaptability, and ease of communication function at a more stable and flexible level than do families that lack one or more of these features. Pless and Satterwhite (1973), in contrast, define family functioning as the dynamics of everyday life: i.e., the way in which the family as a unit operates across dimensions such as intra-family decision-making, marital communication, cohesiveness, satisfaction, and happiness and closeness of the family unit. Geismar and associates (1962) do not give a specfic definition for family functioning but do list the categories of family functioning. These categories are: (1) family relationships and family unit, (2) individual behavior and adjustment, (3) care and training of children, (4) social activities, (5) economic practices, (6) household practices, (7) health conditions and practices, (8) relationship to social workers, and (9) use of community resources.

Smilkstein (1978) defines family functioning as that behavior which promotes emotional and physical growth and maturation of all members. For Smilkstein, the concept encompasses five basic components: adaptation, partnership,

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growth, affection, and resolve. According to Smilkstein, these components represent the common themes in the social science literature dealing with families. In the paragraphs that follow, Smilkstein's definition of the components of family functioning are defined and compared with the other authors' concepts of family functioning.

Adaptation is defined by Smilkstein (1978) as family members aiding each other in times of need and accepting help or assistance from friends and community agencies for problem-solving. To assess adaptation within a family one might for example, ask the following questions. Do the family members pull together and give each other assistance when a crisis develops within a family? Is the family willing to turn to community resources for assistance when the resources within the family are not sufficient to keep the family functioning?

Given these examples, it be that can seen Smilkstein's definition of adaptation is consistent with other definitions. For example, Rakel (1977) refers to adaptation as adaptability. He states that adaptability makes it possible to adjust and respond to sudden or relatively unexpected changes. Further, Pless and Satterwhite (1973) refer to adaptation when they consider the ability of individual member's to turn to other family members to help solve problems. And, although Geismar and his associates (1962) do not adaptation discuss

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specifically, they do imply the concept when they state that use of community resources is important to family functioning. Each of these resources can be useful in the time of crisis as well as for everyday living. Thus, it appears that each of the author's views are basically consistent with Smilkstein's view of adaptation.

Partnership, according to Smilkstein (1978), defined as the way in which family members communicate with each other and make decisions about such matters vacation, finances, medical care, large purchases, and personal problems. Rakel (1977), while not using the term partnership, refers to free communication and states it contributes to the consistency of open and honest and honest among members, i.e., open relationships relationships contribute to partnership. Similarly, Pless and Satterwhite (1973) do not identify partnership as such, but they too consider family communication decision-making as vital components of family functioning. Finally, Geismar and associates (1962) consider relationships and family unity, including relationships, parent-child relationship, relationships among children, and family solidarity, to require family communication and decision-making. Thus although Rakel (1977), Pless and Satterwhite (1973), and Geismar and associates (1962) do not identify partnership as such, each has identified areas of family functioning that are consistent with Smilkstein's partnership component.

Growth, the third component of family functioning, is defined by Smilkstein (1978) as the way in which family members accept change, promote independence, and share Nurturing often refers to the training rearing of children. But, the concept also can be used to refer to freedom available to the individual within the family to make a change as well as the independence he/she is allowed to change. In this sense, chnage is equilvalent to growth. Rakel (1977) refers to this concept as tolerance which he says allows for individual freedom and development. In addition, Rakel (1977) alludes to the concept when he discipline which provides quidelines for considers acceptable activity and prepares the individual for needs. Geismar and colleagues (1962) also consider growth when they evaluate the family's ability to care for and train children as well as the social activities in which the members are involved. That is, social activities promote growth as well as independence. Each author, then, appears to consider promotion of growth as an important component of family functioning, although each refers to it differently.

Affection, according to Smilkstein (1978), is defined as the way in which members of the family respond to emotional expressions such as affection, love, sorrow, or anger. In considering affection, the question becomes: what is the family member's satisfaction with the intimacy

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and emotional interaction that exists within a family? Rakel (1977) considers affection when he refers to love. that love provides an atmosphere of states acceptance, and support. So too do Pless and Satterwhite consider affection when they address satisfaction, happiness, and closeness. In contrast, although Geismar and associates (1962) do not single out the component affection, they do consider it when they view family relationships and family unity as well as when they consider the emotional care of children. Each author, then, in his or her own way, indicates the importance of affection as a component of family functioning.

Finally, resolve, as defined by Smilkstein (1978), refers to the way in which members of the family share time, space, and money. Degree of resolve is defined by the individual's satisfaction with the amount of time that family members are willing to share and her/his satisfaction with the amount of money and space allowed for personal use. Rakel (1977) does not refer to anything that may be equated with Smilkstein's resolve. Pless and Satterwhite (1973), however, consider resolve when they refer to the family's cohesiveness, that is, the time the family spends together such as on vacations or on weekends. Geismar and associates (1962) also do not specifically speak to resolve, but they do consider the family's economic practices and their household practices, practices equivalent to Smilkstein's

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reference of sharing of money and space. Thus, other authors give variable emphasis to resolve as defined by Smilkstein.

In summary, it can be seen that various authors define the components of family functioning somewhat differently. Nevertheless, there appear to be common themes represented in all their writings. Thus, since Smilkstein's components of family functioning encompass the concepts mentioned by the other authors and since his definition of each component is clear, his definitions of the five components will be used as a basis for this study.

Smilkstein (1978), Pless and Satterwhite (1973), and Rakel (1977) indicate that family functioning influences the health of patients. Other authors have considered the influence of the family on the health of the individual members as well. For example, Schmidt (1978) conducted a review of the family literature and found affirmation of the importance of the family to the individual's health. In addition, Litman (1974) states that the family constitutes perhaps the most important social context within which illness occurs and is resolved and, consequently, serves as a primary unit in health and medical care. In a similar vein, Freeman (1970) writes that the home environment is conducive to health maintenance and personal development. That is, the extent to which the family functions as a unit affects its capability in health matters. Geyman (1977)

furthermore states that disorders in the family unit can precipitate illness in individual members. Thus, there is agreement that family functioning affects the health of its members.

It appears, then, that family functioning may affect the health of its members and we also know that health is related to compliance behavior. Therefore, it might be expected that the family would influence compliance behavior. Indeed, some studies have been conducted to ascertain the influence of the family on adherence to a regimen and attention now turns to them and their relationship to Smilkstein's (1978) components of family functioning.

Litman (1966), in a study of patients who suddenly found themselves with a severe orthopedic disability, found good response to physical rehabilitation among those patients who received positive reinforcement from their families and poor response to physical rehabilitation among those patients who did not obtain this encouragement. That is, patients whose families were able to adapt to the crisis and give support were more likely to comply with the required regimen. Such ability to adapt in time of crisis is defined by Smilkstein (1978) as the adaptation component of his Family APGAR.

In a similar vein, a study conducted by Oakes and associates (1970) found that perceived family expectations

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were strongly related to the arthritic patient's compliance with the use of a hand resting splint. In addition. Heinzelmann and Bagley (1970), in a study of a group of sedentary middle-aged men who were at high risk for developing heart disease, found that those men whose wives positive attitudes toward a physical conditioning had program were more apt to comply with their physicial conditioning program. The perceived family expectations considered in Oakes and associates' study (1970) and the positive attitude of the wife discussed in Heinzelmann and Bagley's study (1970) suggest that communication, verbally or nonverbally, took place between the family members or partners and encouraged compliance. Smilkstein (1978)considers communication between family members an aspect of partnership and partnership is a component of functioning. In this sense then, Heinzelmann and Bagley's (1970) and Oakes and associates' (1970), findings suggest that partnership is related to compliance behavior. Furthermore, a study by West (1977) suggests that receiving support from other family members can result in an increased probability of compliance behavior. In a survey of smokers who had attended a smoking clinic five years earlier, West (1977) found that two-thirds of the quitters had spouses who made it easier to quit while only slightly more than onethird of the nonquitters received this support. smoking, of course, requires a change in life habits.

According to Smilkstein (1978), family members who encourage and/or accept change and give mutual support and guidance promote growth of the family members. Families in the West (1977) study who gave support and accepted change (Smilkstein's growth component of family functioning) resulted in a better probability of compliance behavior.

Moreover, a review of research literature bv Backeland and Lundwell (1973) found that in 19 out of 19 studies, social isolation and/or lack of affiliation with another person was a major cause for the discontinuation of treatment among psyciatric patients. Such patients, then, lacked the emotional and functional support potentially available to those who are in close contact with significant others. In this sense, the findings of Backeland and Lundwell (1973) suggest that Smilkstein's concept of resolve -- i.e., a commitment to devote time, wealth, and space with other members of the family for physical and emotional nurturing -- is related to compliance behavior, or, at least, continuation with treatment.

Finally, each of the studies cited suggests that emotional support and caring by other family members is conducive to compliance behavior. That is, by being present in times of need and sharing emotional experiences, family members convey support, thereby increase the likelihood that a patient will comply with treatment regimens. Such emotional support and caring are referred to by Smilkstein

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(1978) as the affection component of family functioning.

It appears then, that each of the individual components of family functioning, as defined by Smilkstein (1978), do have an influence on compliance behavior. However, the relationship of compliance behavior to an individual's perception of the total concept of family functioning has not been studied to the best of the authors knowledge.

In summary, the way in which family functioning influences the health state is a question that has been explored. But, the total concept of family functioning as it relates to compliance behavior has not been studied. The purpose of this study is to investigate the relationship between perceived family functioning and perceived compliance behavior of the adult onset diabetic, a heretofore neglected subject.

## Summary

A review of the literature showed that the chronically ill patient often has trouble complying with prescribed treatment. Furthermore, in chronic illness, such as adult onset diabetes, compliance behavior is necessary for an individual to reach her/his maximum potential for daily living. Moreover, research showed that certain aspects of family functioning appear to influence compliance behavior which affects the health state of patients with chronic illnesses such as hypertension, arthritis, and

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orthopedic disabilities. Therefore, it is reasonable to expect that there may be a relationship between the total concept of family functioning and compliance behavior in patients with the chronic illness, diabetes.

To continue then, perception is defined as individual's image of reality and since an individual's perception may influence her/his behavior, for the purpose this study, perceived family functioning will measured. Since objective measures such as outcomes have limitations in studies based on a one time measurement, perception of compliance will be measured since there appears to be a relationship between perceived compliance behavior and actual compliance behavior. Furthermore, since nursing is concerned with individuals reach their maximum potential for daily living, the relationship of these variables to nursing theory will be discussed.

## Nursing Theory

Man and his environment is the central focus for the framework of nursing (King, 1971). The aim of nursing is to give assistance to individuals to help them cope with a health problem or adjust to interference in their health state (King, 1971). In other words, the aim of nursing is to help individuals reach their maximum potential for daily living. King's (1971) theory is based on four universal concepts. These concepts are perceptions, social systems,

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interpersonal relationships, and health. These four universal concepts from King's theory were used as a frame of reference for this study which has as its focus perceived family functioning and its relationship to perceived compliance behavior in chronic illness.

Chronic illness, such as diabetes. causes an interference in an individual's health state. Compliance with the therapeutic regimen for diabetes, prescribed by the health care provider, will aid the individual to reach and/or maintain her/his maximum potential for daily living. However, as stated previously, compliance with a therapeutic regimen, especially in chronic illness, is not easy. The nurse realizes there are many barriers to compliance. One facet of the nurse's role is to help the individual to identify and overcome barriers, and enable her/him to use her/his potential ability to function.

To assist an individual to identify and overcome barriers to compliance, the nurse utilizes the nursing process. The nursing process involves assessing the problem, planning an intervention, implementing the intervention, and evaluating the outcome.

In chronic illness, there is a need for the nurse to assess if the patient may be having a problem with compliance behavior. A cue that a problem may exist could be obtained by reviewing the objective parameters from the patient's records such as blood glucose, degree of

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glycosuria, alpha hemoglobin, or obesity. It may be a cue to noncompliance with the diabetic regimen if repeated measurements of one or more of these objective parameters are not within normal limits.

It is not only necessary to assess the objective parameters in relation to compliance behavior, but an integral part of an assessment is an exploration of the patient's perceptions since man functions in terms of his perceptions (King, 1971). According to King perception is each individual's image of reality or her/his conscious awareness. Therefore, the nurse should the patient's \perception of her/his compliance behavior. The patient's perception of her/his compliance behavior is important since if the patient does not perceive herself/himself as non-compliant, the patient will not realize a need to plan strategies to improve compliance. Thus, perception is a necessary concept for the nurse to deal with in the delivery of health care.

In addition, the patient's perception of his/her social system also influences her/his behavior (King, 1971). King (1971) states "the social system is composed of groups of individuals joined together in a network or system of social relationships to achieve common goals developed about a system of values with an organized set of practices and the methods to regulate practices and administer the rules". The family unit is a social system in that it is a group of

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individuals joined together in a network. King (1971) states that man's adaptation to life and health is influenced by her/his perception of environmental factors. Thus, since the family unit is a part of the environment of the patient, it is reasonable that the individual's perception of her/his family would influence adaptation to life and health.

Further, according to King (1971), man functions in a social system (family unit) through interpersonal relationships, i.e., interaction of individuals for some purpose or goal. Rakel (1977) states that the interaction of family members determines how the family functions. Therefore, the interpersonal relationships between and among family members determines how the family functions. Thus, since it seems the family influences adaptation to life and health, it is reasonable to expect that the interpersonal relationship among family members, i.e., family functioning, also would influence adaptation to life and health.

To continue then, man's perception of his interpersonal relationships (family functioning) within the social system (family unit) influences the individual's life and health. The family unit may be a source of strength to an individual or it may have a negative influence on the patient's health. Health is the dynamic state in the life cycle of an organism which implies continuous adaptation to stresses in the internal and external environment through

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optimum use of one's resources to achieve maximum potential for daily living (King, 1971). An unsatisfactory perception of family functioning by the adult onset diabetic may be a negative stressor in the individual's life. The individual may have difficulty adapting to this negative stressor and in turn the unsatisfactory perceived family functioning may be affecting the patient's compliance behavior. Compliance behavior in the adult onset diabetic is essential to attaining or maintaining health.

The nurse should further recognize that human behavior has multiple determinants and many factors may influence the compliance behavior of adult onset diabetic patients. The limitations of research usually confine a study to examine only one or two determinants of behavior at a time. Nevertheless, the nurse must view the patient holistically and evaluate not only the relationship between perceived family functioning and perceived compliance, but must consider the effect of confounding variables on the perception of compliance behavior as well.

The confounding variables examined in this study were: (1) complexity of regimen; (2) number of chronic illnesses other than diabetes; (3) number of years with diabetes; and (4) hospitalization for diabetes. These are only a few of the additional variables that may influence compliance behavior. If the confounding variables examined in this study do not appear to alter the perception of

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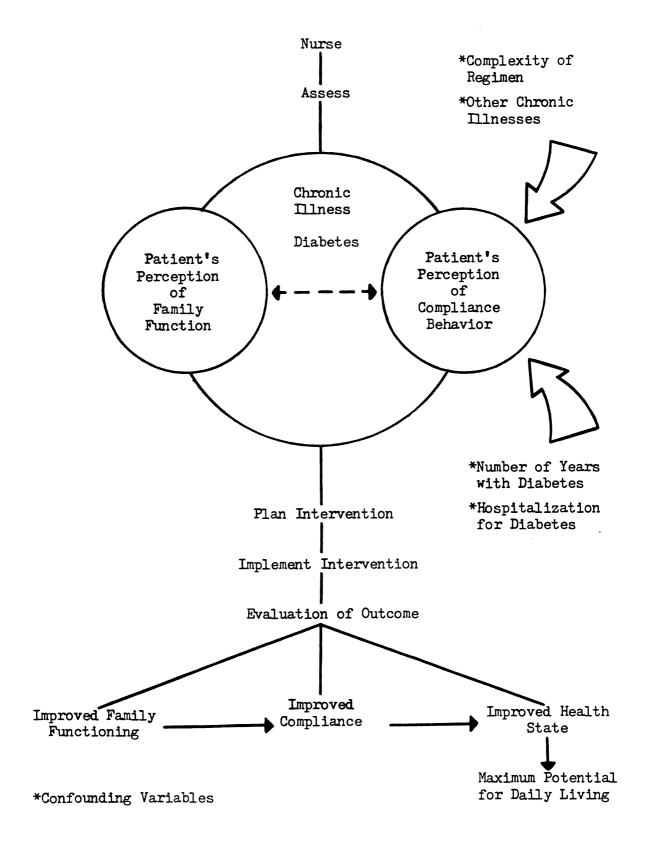
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compliance behavior, and a relationship can be shown between the patient's perception of family functioning and the patient's perception of her/his compliance behavior, then, the nursing action may center on assisting the patient in developing strategies to improve perceived family functioning.

Following the patient's implementation of planned strategies, it is necessary for the nurse to evaluate if the strategies improved the patient's perception of her/his family functioning and to determine if the improved perceived family functioning resulted in improved perceived compliance behavior. The improved compliance behavior may be based on the perceptions of both the patient and the nurse. Finally, the nurse and the patient can evaluate together if the patient's maximum potential for daily living was reached. The entire process is summarized in Figure 1.

In this chapter the concepts reviewed were compliance behavior in chronic illness and family functioning and the family's influence on compliance behavior. These concepts were then reviewed in relationship to King's nursing theory. In Chapter III the review of the literature will be presented.

FIGURE 1. An Integration of the Nursing Process as it Relates to Family Functioning and Compliance Behavior in Chronic Illness.



### CHAPTER III

### REVIEW OF THE LITERATURE

# Introduction

The review of the literature includes a discussion of research studies and papers that are related to compliance behavior, compliance behavior in chronic illness, and family functioning. First, the magnitude of the problem of compliance, the variables that have been investigated concerning compliance, and approaches to measure compliance will be discussed. Then, studies concerning compliance and chronic illness focusing mainly on diabetes will be reported. Finally, a review will be presented of literature concerning the identification of components of family functioning, measurement of family functioning, and the family's influence on compliance as related to the components of family functioning. The organization of literature will be guided by the following order: (1)synopses of the literature pertinent to the major subjects will be presented within individual sections; and (2) each section will be summarized and the strengths and limitations of the studies reviewed discussed.

# Compliance Behavior

In this section the magnitude of noncompliance, the variables that have been investigated, and the approaches

that have been used to measure compliance behavior of the adult onset diabetic will be discussed.

# Magnitude of Noncompliance

Past research seems to suggest that compliance with a therapeutic regimen is a problem to both the patient and the health care provider. Haynes and his colleagues (1979) reviewed 537 studies concerning compliance behavior found that one-third of ambulatory patients with chronic do not follow their prescribed treatments. illness Blackwell (1973) reviewed over 50 studies on medication and found that failure to take medication occurred in 25 to 50 percent of all outpatients. contrast, Davis (1966) states that taking medication is one of the easier aspects of the regimen to follow as compared with restrictions on behavior or changes in personal habits. Davis' (1966) statement suggests that noncompliance with restrictions on behavior or with changes in personal habits may even surpass the percentage of 25 to 50 percent noncompliance reported by Blackwell. Indeed, Davis (1966), in his review of the literature, revealed that noncompliance rates may soar as high as 93 percent although in almost half of the studies he reviewed, the noncompliance rate fell within the range of 30 to 35 percent.

According to Davis (1966) the wide range in compliance rates reported in different studies is due to the various populations considered, the various methods used to

collect data, and the variety of medical problems and regimens investigated. Moreover, Marston (1970) states that it is usually misleading to compare compliance rates from different studies due to the wide variations in operational definitions of compliance, the lack of truly objective measures of compliance, and the problem of precision of analysis that occurs where compliance is based on several different medical recommendations. Nevertheless, regardless of the shortcomings inherent in comparisons of compliance rates across studies, it seems that the problem of compliance is a substantial one and there is still much that needs to be learned concerning why patients do or do not follow treatment regimens.

## Variables Reviewed

The literature shows that many variables have been studied to ascertain their influence on compliance behavior. For the purposes of this research selected variables will be discussed, i.e., demographic data, knowledge, features of the disease, and features of the regimen. It is realized that a considerable body of published data exists on the relationship between compliance and health beliefs. Health beliefs are described as the perceived susceptibility to disease and its complications, the perceived severity of the disease, the perceived benefits of care, and the perceived barriers such as physical, psychological, or financial costs related to the therapeutic regimen. These beliefs have been

shown to correlate positively with compliance behavior. However, many of the studies that examined this relationship have been conducted on mothers of children with acute illnesses (Becker et al., 1972; Charney et al., 1967; Francis et al., 1969). More recent studies, concerning the health beliefs of adults with chronic illness and compliance behavior, have revealed conflicting data. (Cerkoney and Hart, 1980; Ferguson and Boles (1979); Green et al., 1979; Hershey et al., 1980; Taylor, 1979). Studies have also shown that doctor-patient relationships have an effect on compliance behavior (Haynes et al., 1979). However, in an effort to narrow the scope of the study, doctor-patient relationships and health beliefs will not be investigated.

Demographic Variables. Demographic variables studied in relationship to compliance have included age, sex, education, socioeconomic status, income, occupation, marital status, and race. Haynes and associates' (1979) extensive review of the literature revealed that the vast majority of studies found no significant association between demographic variables and compliance behavior. However, a few studies did suggest there may be some relationship between specific demographic variables and compliance. For example, Bille (1977), in a study of myocardial infarction patients, found that the older person was more likely to follow the medical regimen although he offered no explanation of this finding.

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By contrast, Blackwell (1973), who has conducted much research on compliance and drug therapy, found that medication errors and noncompliance occur most often at extremes of age, i.e., the very young do not comply possibly due to the taste of the medication and the very old have difficulty complying possibly due to forgetfulness or self-neglect.

(1971)found Furthermore, Vincent correlations between age, sex, and compliance behavior. In her study of patients with glaucoma, Vincent showed that women from 45 to 64 years of age were more likely to comply with treatment regimens than men. Vincent suggested that the difference between sex and compliance was possibly due to the fact that middle age women usually have more time to give attention to the specifics of the treatment regimen because children are grown, while, men still have occupational obligations that require their attention. No recent studies have been located, however, that substantiate Vincent's finding. Moreover, Vincent's (1971) findings may no longer be true since more and more women also have occupational obligations. By contrast, a review of the literature by Davis (1966) also revealed that in three out of four studies of tubercular patients, females were more likely to default than males concerning medications, but females were more likely to keep clinic appointments. Davis, however, did not suggest a reason for the difference.

Similarly, some research has shown a relationship between socioeconomic status, including income and occupation, and compliance. That is, Davis (1966), in a review of studies assessing socioeconomic status, reported that most found that lower class individuals were least likely to comply. Marston (1970) and Haynes and associates (1979), however, in more recent reviews of the literature, suggest that socioeconomic status may not be as strongly related to compliance as previously thought.

In summary, although a few studies suggest there may be a relationship between specific demographic variables and compliance, the majority of studies found that when demographic variables are examined apart from other variables they are rarely predictive of compliance behavior. Demographic variables, however, are useful for descriptive purposes to depict the sample studied.

Knowledge. Conflicting data exists regarding the relationship between compliance and knowledge. A positive association was found by Watkins and associates (1967) in a study based on direct observation and interview of diabetic patients. That is, those who had higher scores on knowledge tests concerning various aspects of diabetes had better home management scores and more accurate compliance treatment than those with low knowledge scores. Williams and associates (1967) also found that the more patients knew about their disease and its management the better they carried out recommended therapy. However, these researchers found no significant correlation between performance and control of diabetes as measured by such parameters as blood sugar levels, urine glucose levels, and body weight. Williams and his colleagues (1967) suggested that a possible explanation for this finding was that patients who were in poor control may have been hospitalized more and may have had more instruction on caring for diabetes. Thus, more frequent instruction may have resulted in the patients' increased knowledge concerning diabetes and, accordingly, more accurate compliance with most aspects of treatment.

In a similar vein, Tagliacozzo and associates (1970), in a study of 159 medically indigent blacks with chronic illness, found that knowledge of illness and its complications, as measured by a paper and pencil test, was related to the likelihood of continuation of attendance at the medical clinics over a prolonged period of time. Those with knowledge of illness and its complications were more likely to continue in care than those with low knowledge who tended to terminate care prior to their fourth visit.

In contrast to the findings just discussed, studies conducted by Bille (1977) on myocardial infarction patients, Blackburn (1977) on chronic hemodialysis patients, and Vincent (1971) on glaucoma outpatients, all found no association between knowledge of the disease and regimen and compliance behavior. Moreover, Donabedian and Rosenfeld

(1964) found no association between understanding the regimen and compliance behavior, as measured by the accuracy and completeness with which the patient could describe the recommendation. However, the researchers report this negative finding may be due to inadequacies of their assessments of understanding since the finding was at variance with the reasons actually given for lack of compliance. That is, reasons for noncompliance frequently seemed to reflect poor understanding on the part of the patient.

In summary, data regarding the relationship between knowledge and compliance is conflicting. This conflict suggests that transmitting information alone may not be enough to overcome noncompliance. Knowledge may be necessary but not sufficient to insure compliance behavior. That is, an individual can know something and still not consider its implication for her/his behavior.

Disease Features. The features of the disease to be reviewed in this section are diagnosis, severity of disease, and degree of disability. Of the studies reviewed, two assessed diagnosis and its relationship to compliance (Diamond et al., 1968; Hulka et al., 1975). Diamond and investigated patients admitted colleagues (1968) for rehabilitation service who had suffered fractures, amputation, spinal dysfunction, or peripheral neuropathy. Hulka and associates' (1975) research dealt with adult onset

diabetics and congestive heart failure patients. Neither study showed an association between diagnosis and compliance behavior.

Severity of disease was investigated in several studies of patients with general medical complaints (Davis, 1968), patients admitted with orthopedic or neurological problems for rehabilitation (Diamond et al., 1968), patients with hypertension (Podell et al., 1976), and patients with adult onset diabetes and congestive heart failure (Hulka et al., 1975). None of the studies found an association between severity of disease and compliance behavior.

Two studies reviewed considered the degree of disability as a function of compliance. Hulka and associates (1975) in their investigation of adult onset diabetes and congestive heart failure patients found no association between degree of disability and compliance behavior. By contrast, research conducted on chronically ill patients by Donabedian and Rosenfeld (1964) showed that the more severe the disability, the more compliant the patients. Haynes and other (1979) believe that the positive association found can be explained by the fact that increased supervision accompanies increased disability. As a result, people with increased disability are compliant.

In summary, all but one of the studies reviewed (Donabedian and Rosenfeld, 1964) found that no association

exists between compliance behavior and diagnosis, severity of disease, and degree of disability. Therefore, the search for factors that influence compliance behavior has continued.

<u>Features of the Regimen</u>. Several aspects of the treatment regimen appear to have an influence on compliance. In this section, duration of treatment, complexity of regimen, and types of regimen will be considered.

The duration of treatment has not been shown to have a consistent effect on compliance. For example, Blackburn (1977), in an investigation of chronic hemodialysis patients, found that patients' adherence to their diet decreased with time, as measured by blood levels of potassium and phosphorus. Similarly, Haynes and associates (1979), in a review of the literature, also found that adherence to treatment decreases with time. By contrast, Ferguson and Boles (1979) found no significant relationship between length of illness and compliance in patients with rheumatoid arthritis.

Data do exist, however, that suggest that complexity of medical regimen does influence compliance behavior. For example, Hulka and associates (1975), in a study of adult onset diabetic and congestive heart failure patients, found that compliance was lower for patients for whom both drugs and other recommendation were made. In a similar vein, Green and associates (1979) found that the more drugs the

hypertensive patients were prescribed, the less likely they were to say they complied with treatment or to meet criterion of blood pressure control.

Furthermore, there are indications in the literature that some aspects of a medical regimen are less likely to be followed than others. For example, in a studv hypertensive patients adherence to antihypertensive medical regimens, Kirscht and Rosenstock (1977) found that patients' compliance with their dietary regimen was considerably less their compliance with their medication than Donabedian and Rosenfeld (1964) suggest, based on a review of the literature, that the differences in compliance with the two treatments are due to the difficulties inherent inducing change in patients dietary habits. That restrictions which necessitate relinguishing personal habits, i.e., dietary changes, are more difficult to follow than those that do not require general modifications behavior, i.e., taking medications (Davis, 1968).

In summary, duration of treatment, complexity, and type of regimen may affect compliance. Therefore, continuing to investigate the features of the regimen as related to compliance behavior may be worthwhile pursuing. In a subsequent section concerning chronic disease and diabetes, it will be shown how these aspects of the regimen relate to chronic illness.

# Approaches to Measure Compliance

Several approaches have been employed to measure the adult onset diabetics compliance with taking medication and following diet restrictions. These approaches include: (1) objective measures such as pill counts, drug excretion tests, and alpha hemoglobin; (2) clinical outcomes such as blood sugar levels, urine glucose levels, and weight; and (3) subjective measures such as direct observation, physician report, and patient report.

Objective Measures. According to Gordis (1979), research shown that pill count as an indirect measure of compliance behavior is open to serious question. (1979) suggests that this is so because patients may throw the remainder of their medication away in order to appear compliant. Gordis (1979) also notes that drug excretion compliance. tests, another objective measure of limitations. These limitations are the result of the fact that assessment cannot be made accurately if the absorption and excretion patterns of the patients regarding the medication is not known or if variations among patients as to time the medication was taken and metabolism of the drug are not known. Moreover, Gordis (1979) notes that drug excretion tests are limited in that often it is not possible detect medication or their by-products without to detectable label. Furthermore, drug excretion tests should

be based on periodic assessment.

Alpha hemoglobin, however, has been found to be a somewhat better indicator of compliance behavior of the diabetic than other objective methods. This is so because elevated blood sugar has a cummulative effect on the alpha hemoglobin because glucose attaches to the hemoglobin and the glycosylated alpha hemoglobin remains elevated for four to six weeks. Moreover, Tattersall and his associates (1980) state that the test has the advantages (1) of being objective, (4) of being independent of the patient's cooperation, (3) of and having the ability to indicate diabetic control by a single number that reflects prevailing blood glucose in the preceding few weeks. Nevertheless, Leslie and associates (1979) state that a single alpha hemoglobin estimation may relate to a shorter period of than once was suggested, and therefore, hyperglycemia cautioned against drawing conclusions concerning compliance behavior from a single alpha hemoglobin estimate.

To sum up, then, objective measures have the advantage of being independent of the subject's cooperation. However, objective measures have several limitations as well such as patients throwing pills away to appear compliant in the case of pill counts, difference in individual metabolism for drug excretion tests, and the questionable accuracy of basing an estimation of compliance behavior from a single measurement of alpha hemoglobin.

Clinical Outcome Measures. Clinical outcome measures frequently have been used in an attempt to detect compliance behavior in the diabetic patient. The rationale behind the use of such measures is that diabetic control is the desired outcome and blood sugar and urine glucose levels, parameters used to view diabetic control, indicate compliance. Diabetic control, however, is limited as a measure of compliance behavior since factors such as stress, infection, exercise, and individual metabolism, as well as appropriate medication and dosage, all may affect the individual's response to her/his therapeutic regimen. In addition, blood sugar gives only a fragmentary glimpse of the patient's metabolic status (Bondy & Felig, 1971). Futhermore, urine glucose is only a gross estimate of diabetic control because blood sugar is well above normal limits before it reaches the renal threshhold and glucose is spilled into the urine (Tattersall et al., 1980). At the same time, the renal threshhold for glucose varies more widely in diabetic patients than is generally recognized (Tattersal et al., 1980).

Still another clinical outcome measure used to detect compliance behavior is weight maintenance or weight loss. This is so because weight maintenance or weight loss gives an estimate of compliance with the diabetic diet frequently prescribed for the generally overweight adult onset diabetic (Cohen & Etzwiler, 1976). It is necessary,

however, to view the weight pattern over an extended period of time because a patient may weigh 250 pounds and not appear to be complying, yet, a year ago he/she may have weighed 350 pounds thus indicating he/she is complying.

In short, then, clinical outcome measures are useful in that they are objective. However, a single measurement of clinical outcomes is generally not adequate to base an estimation of compliance behavior because other factors besides adherence to a therapeutic regimen may influence the results of the outcome measures.

Subjective Measures. Subjective measures such as direct observation, physician report, or patient report also are not without their limitations. Direct observation involves patient's compliance with diet, medication, follow-up appointments by someone other than the patient, a trained observer, family member, or e.q., According to Dunbar (1979), for such methods to be accurate, not only must the observer have clear instructions on what behaviors are to be observed and recorded but the patient also should be unaware that he/she is being observed. Direct observation has an advantage in that it may detect misinformation regarding the therapeutic regimen. this method does have several disadvantages. For example, the observer's emotions, attitudes, and prejudices result in inaccurate report of findings. In addition, the observer may see what he/she wants to see or what he/she

expects to see, thereby recording a more positive rating than a person with a less positive general impression might give.

Still other subjective measures frequently used to estimate compliance are physician and patient reports. that physicians' estimates of Gordis (1979) states compliance are of very limited value since physicians are unsuccessful in identifying noncompliant patients and tend to overestimate compliance behavior as well. By contrast, Haynes and his colleagues (1979) state that self-report compliance by the patient is as effective a means measuring compliance as more objective means. They note, however, that patients tend to overestimate their compliance with a therapeutic regimen. Nevertheless, studies conducted to substantiate the veracity of patient report, found a significant relationship between self-report of compliance with taking medication and blood pressure control (Green et al., 1979; Hershey et al., 1980).

The findings of these researchers were supported by Ferguson and Boles (1979) in an investigation undertaken to verify patient-report of compliance behavior. Ferguson and Boles examined the relationship between lack of belief in benefits of treatment and compliance behavior of 40 rheumatoid arthritis patients with taking aspirin and following an exercise program. Patients self-reported compliance with taking aspirin and following an exercise

program and verification of these self-reports was achieved (1) by obtaining salicylate levels on 12 of the 40 patients participating in the study; and (2) by interviewing a family member of nine of the forty patients about patient's compliance with the exercise program. Ferguson and Boles (199) found that in ten of the twelve patients the blood levels confirmed the patients' reports. Moreover, they found that 6 of the 9 family members interviewed also verified the patient report providing support for Haynes and his colleagues' (1979) finding that patients tend to overestimate compliance behavior.

Nevertheless, even though patients may tend to overestimate their compliance behavior somewhat the above studies suggest a correlation between perceived compliance behavior and actual compliance with the therapeutic regimen may exist. Thus, further investigation regarding the relationship between perceived compliance behavior and actual compliance would be beneficial.

## Summary of Compliance Literature Review.

The review of the literature revealed that approximately one-third to one-half of all patients on medical regimens do not comply with their treatment regimens. As a result, many studies have been conducted to ascertain which variables influence compliance. Most of the studies reviewed were cross sectional and descriptive in design. In addition, the sample sizes were small and from

convenience samples, therefore, the results cannot be generalized. Nevertheless, most of the findings were consistent from one study to the next.

The review further revealed that demographic variables such as age, sex, education, socioeconomic status, income, occupation, marital status, and race when examined apart from other variables, were rarely predictive of compliance behavior. However, demographic variables were useful for descriptive purposes.

It was found in the review that conflicting data exists concerning knowledge of the disease and regimen and compliance behavior, i.e., either there was a positive association between knowledge and compliance or there was no association between knowledge and compliance. By contrast, it was found that the majority of the studies investigated the relationship between the features of the disease (i.e., diagnosis, severity of disease, and degree disability) and compliance behavior, association between these two variables. On the other hand, features of the therapeutic regimen (i.e., complexity, duration, and type of regimen) have been shown to have an effect on compliance behavior. In short, then, it may be worthwhile to continue to investigate the possibility of a relationship between compliance and features of therapeutic regimen.

Several approaches were reviewed that could be used

to measure compliance behavior. It was found, however, that each method of measurement has its shortcomings. For example, direct observation is subject to bias, physician report has been shown to be unreliable, a one time measurement of clinical outcomes is not sufficient to estimate compliance behavior, and patient self-report of compliance behavior tends to overestimate compliance. Nevertheless, data suggest that a relationship between perceived and actual compliance behavior exists and that this may be a preferred method of measuring compliance behavior in the absence of more definitive measures.

In the next section literature concerning chronic illness and its relationship to compliance behavior will be considered.

## Chronic Illness - Diabetes

Research suggests that compliance with a therapeutic regimen is a problem to both the patient and the health care provider. The research also suggests that compliance behavior is more of a problem when compliance with a therapeutic regimen is extended over a period of time. In this section, the review of the literature concerning the nature of chronic illness will be discussed, as well as the types of chronic illnesses that have been studied in relation to compliance behavior. The studies that investigate the chronic illness, diabetes, in relation to compliance behavior, will be discussed in more detail.

Chronic illness encompasses a variety of disorders and may include any impairment of bodily function that extends over a period of time. In contrast to the patient with an acute illness of limited duration, the patient with a chronic illness is faced with long-standing conflicts and adjustments to which he/she must adapt (Abram, 1972). Chronic illness frequently requires long-standing or permanent restriction of activities, long-standing or permanent changes in diet, long-term administration of medications, and a long-standing or permanent strain on the individual's financial resources.

A wide range of studies exist that have assessed chronic illness and compliance. Of the studies reviewed, investigated the chronic illnesses were: myocardial infarctions and congestive heart failure (Bille, 1977; Hulka et al., 1975 & 1976 ); renal disease (Blackburn, Steidl et al., 1980); neurological and muscular disorders (Diamond et al., 1968); arthritis (Ferguson & Boles, 1979; Oakes et al., 1970); hypertension (Green et al., 1979; Podell et al., 1976; Taylor et al., 1979); glaucoma (Vincent, and 1971); and diabetes (Bowen et al., 1961; Cerkoney & Hart, 1980; Hulka et al., 1976; Williams et al., 1967; Watkins et al., 1967). Most of these studies focused on a population with a particular diagnosis or compared patients with similar types of diagnoses such as congestive heart failure and adult onset diabetes. No

studies were found that compared compliance among patients with acute versus chronic illness.

In spite of the lack of existent comparative studies, most authors agree it is difficult to comply with a regimen prescribed for a chronic illness (Barsky, 1976; Blackwell, 1973; Davis, 1968a). This is so because it has been found that noncompliance increases when: (1) regimens require more extensive behavioral changes (Davis, 1968b; Donabedian & Rosenfeld, 1964; Kirscht & Rosenstock, 1977); (2) are more complex (Green et al., 1979; Hulka et al., 1975); and (3) must be continued over time (Blackburn, 1977; Hershey et al., 1980).

These findings seem particularly applicable to the chronic disease diabetes. First, the treatment regimen for the disease requires that the patient make extensive behavioral changes. For example, dietary habits and activity patterns must often be altered. Second, the regimen for the disease frequently is complex, requiring dietary restriction, taking medication (insulin or oral hypoglycemics), testing urine, engaging in regular exercise, and practicing good general hygiene including special foot care. And third, the diabetic regimen must be continued throughout the patient's lifetime in order to maintain control of her/his diabetes.

Because compliance is critical to diabetic control, several studies have used the clinical outcome of diabetic

control as a surrogate to measure compliance behavior. The underlying assumption of these studies has been that the patient whose diabetes is controlled is a compliant patient. For example, Hulka and her associates (1975) investigated doctor-patient communication and outcomes among 242 diabetic patients who sought care from private physicians to assess compliance. In the study, both patients and physicians were questioned on instructions provided for diabetic management and self care. In addition, clinical data were collected concerning frequency of hypoglycemic reactions, level of blood sugar, frequency of urine sugars greater than 2+, maintenance of appropriate weight in relation to height, and the occurrence of acidosis resulting in hospitalization. And, as an additional measure of compliance, information was gathered on appointments kept and the appropriate use of prescription drugs. The results of the study showed that no relationship was found between Doop doctor-patient communication and diabetic control.

In a similar vein, two intervention studies have been conducted to measure the effects of patient teaching on diabetic control. An early study by Bowen and colleagues (1961) investigated the effects of participation in a planned program instruction taught by registered nurses on 51 insulin dependent diabetic patients. Following the programed instruction, tests were administered to patients during individual interviews to assess their knowledge,

skills, and attitudes. In addition, data on blood sugar levels, weight gain, and levels of sugar in the urine were abstracted from the patients' medical records. The findings of the study showed no significant difference between knowledge of diabetes and its management and diabetes control.

The more recent intervention study, conducted by Etzwiler and Robb (1972), investigated the acceptance and instructions effectiveness of a programmed machine juvenile diabetics and their parents. It was found that both young diabetics and their parents had increased knowledge of diabetes and its management following programmed instruction, and the information acquired was retained for at least three months. However, the findings showed that no significant change in fasting blood sugar levels or the amount of urine glucose accompanied the acquisition of knowledge.

Still another intervention study, conducted by Tagliacozzo and associates (1974), evaluated patient teaching and its effects, not on clinical outcomes, but rather on behavioral outcomes. The subjects in the study were black clinic outpatients with diabetes, essential hypertension, cardiovascular disease, and gastrointestinal illness who received instruction on diabetes in a classroom situation. Patient compliance was measured by regularity of adherence with scheduled visits over a prolonged period of

time, adherence with the request to take medications, and adherence with requests for laboratory tests and visits to other clinics. It was found that the effects of nurse intervention in the form of patient teaching were only slightly associated with patient compliance behavior as measured by behavioral outcomes.

Descriptive studies also have been conducted investigate the relationship between control of diabetes and knowledge (Williams et al., 1967; and Watkins et al., 1967). In Williams and his associates' (1967) study, a sample of two hundred and eleven adult insulin-dependent diabetics were drawn from four settings and their knowledge of diabetes was tested and correlated with diabetic control, as measured by body weight, presence or absence of insulin reactions, and blood sugar or urine glucose levels contained in medical records. In addition, data concerning urine qlucose, insulin reactions, and episodes of acidosis were collected from patients via interviews. The findings showed knowledge about diabetes was inversely correlated control, i.e., patients who knew more about diabetes were in Williams and his associates (1967) state poorer control. that a possible explanation for this is that the patients in poor control have more experience with the problems. resulting in more attention being paid to their disease. This increased attention may facilitate increased learning.

The Watkins and associates' (1967) study incorporated subjective measures of the variables interest rather than objective measures only. Sixty of the subjects included in the above study were visited in their home by two public health nurses and a medical student who, via interview and observation using a structured protocol, assessed the subjects' over-all knowledge of diabetes and actual home management. The analysis of these data showed no significant correlation between compliance and control but a relationship between knowledge and compliance. other words, the more patients knew about the disease, the better they carried out recommended therapy. But, their compliance was not reflected in better outcomes. This would suggest that other variables besides compliance behavior may influence the outcome.

In short, both the Williams and associates' (1967) and Watkins and associates' (1967) studies found a high number of patients in poor and very poor diabetic control. Moreover, Williams and associates (1967) found several factors to be associated with poor control. First, the strongest association was found between age of onset of diabetes and control. That is, the juvenile onset diabetic much more difficult to control than adult onset was diabetics. Second, psychic stress affected control, i.e., the greater the degree of family stress, the poorer the control of diabetes. Third, the greater the

satisfaction with the physician the better the diabetic control. Fourth, in general low socioeconomic status does not appear to limit control; in fact, patients of higher socioeconomic status tended to be in poorer control. Fifth, the larger the household size the poorer the patient's diabetic control. This association was most marked among married males who lived in large households. The authors did not suggest an explanation of these findings. However. Williams and associates (1967) did suggest that perhaps there is still inadequate understanding of the nature of the disease which results in difficulty making appropriate medical recommendations. Thus, there continues to be a need to investigate compliance behavior as it relates to control of diabetes.

In summary, many studies have been conducted to assess compliance behavior in chronic illness. A few of these studies investigated the diabetic patient. Most of these studies have investigated the relationship between knowledge and compliance behavior as measured by outcome, i.e., diabetic control. The results of these studies showed but a tenuous relationship between knowledge and diabetic control. The one study that found a relationship between knowledge and compliance by direct observation and self-report. But, the researchers who conducted this study found no relationship between this subjective measure and control of diabetes.

The lack of relationship between compliance behavior and control of diabetes may be due to other variables that influence diabetic control such as infection, stress, the right medication, and/or the right amount of medication. Or possibly the lack of relationship may be due to the outcome measures that were used to measure control. Bondy and Felig (1971) state that appropriate outcome measures indicate control are difficult to identify. Their assertion is substantiated by Malone's (1976) research in which the accuracy of urinalyses and blood sugar tests performed on juvenile diabetic campers, were analyzed to detect diabetic control. The results of Malone's analysis showed that unreliable testing of urine by patients, inconsistent correlations between the 24 hour excretion of sugar in urine and blood sugar, plus variability in an individual's control as defined by conflicting same-day test results, did not reflect the true metabolic state, i.e., diabetic control. The inadequacy of such objective measures may reflect the fact that they are collected at one point in time. And, as Bondy and Felig (1971) note, it is difficult to obtain entirely satisfactory control measures for clinical studies, especially when a study is based on a one time measurement of clinical parameters.

The research has provided some useful data concerning compliance and diabetes, i.e., lack of relationship between knowledge of disease and treatment

regimen and diabetic control. Yet, no studies were located that evaluated the family's influence as related to family functioning on compliance behavior of the adult onset diabetic patient. In the next section family functioning and the family's influence on compliance behavior will be discussed.

# Family Functioning and the Family's Influence on Compliance Behavior

Management of a patient with chronic disease usually requires that the patient make substantial alterations and adjustment in her/his life style. An alteration in life style affects not only the individual with the chronic disease but, not infrequently, her/his family as well. example, an alteration in diet of one individual within family may affect all individuals within the family. At the same time, the manner in which a family responds to the patient's illness may have a marked effect on the course of the illness (Rakel, 1977). That is, patients who are encouraged by their family members to adhere to their regimens may have fewer complications from their disease than those who do not receive such encouragement. many authors agree it is necessary to treat not only the individual but the individual within the family unit as well (Abram, 1972; Geyman, 1977; Litman, 1974; Schmit, 1978).

In this section identification of components of family functioning, tools to measure family functioning, and

the families influence on compliance behavior as it relates to components of family functioning will be discussed.

#### Family Functioning

The interactional framework is a systematic approach used to study families and is frequently encountered in studies of this basic human unit. According to Nye and Bernardo (1968) the interactional framework is a system of viewing personal relationships within the family. Within this framework. the individual's definition of situation, rather than the objective situation, is stressed (R. King 1969) and attention is focused on love and affection, adaptability, common interests, communication, conflict, problem-solving, decision-making, and reaction (R. King, 1969; Nye & Bernardo, 1968). components of the interactional approach have been utilized in early studies of the family.

For example, Cavan and Ranck (1938) studied families during the economic depression of the 1930's to identify elements of family unity. The major elements of such unity identified were: (1) unity in family objectives; (2) subordination of personal interests to the good of the family as a group; (3) adherence to family ideals; (4) the capacity of the family to satisfy within the family circle the personal interests of its members; and (5) the importance of reciprocal roles and their acceptance by the family members. On the bases of the work of Cavan and Ranck

(1938), Hill (1949) formulated a scale of family integration which he used to study families under stress. Hill's scale included five items: (1) degree of affection; (2) of joint activity of family members; (3) willingness to sacrifice to attain family objectives; (4) degree of family pride; and (5) the degree to which solidarity is present. Hill's work was followed by that of Blood and Wolfe (1960) who, in a classic study, investigated the interaction patterns of husbands and wives. Through interviews with 909 and farm wives, they studied the personal relationships of the husband, wife, and family as a whole. On the basis of their data, they identified decision-making within the family, the division of labor, economic function, affection, understanding, and emotional well-being to be important aspects of relationships among family members.

Each of the above studies identified factors that appear to influence the well-being of the family. Moreover, even though each study applies somewhat different labels to these factors, each group of factors appear to be similar from one study to the next. In addition, the components studied seem to be consistent with the components identified in the interactional approach.

More recently Smilkstein (1975) developed a format to assess the family that appears to be based on the interactional approach. That is, Smilkstein (1975) developed a system of assessing the individual's view of

her/his interactions within her/his family in an attempt to enhance the identification of family problems affecting the patient under the physician's care. Based on family literature, such as that cited above, Smilkstein (1975) identified the following components which he considered inherent in family functioning. These components are: commitment (the pledge to be responsible to and for other members of the family including the contribution of time and adaptation (the capability for (2) modification in the times of crisis or stress); (3) mutuality (the sharing of nurturing needs by members); (4) differentiation (the measure of individual maturation and development that is allowed within the family and (5) intimacy (the caring or relationship that exists among family members). The components of his format appear to be based on many of the factors identified in the interactional framework. On the basis of his format, Smilkstein developed the Family APGAR, an instrument used to assess family functioning to be discussed in the next section.

In summary, early studies identified areas that contributed to family unity. Subsequent studies used these identified areas to develop scales to study family functioning. These studies were descriptive and contributed to the theoretical body of knowledge but no empirical tests were performed. In the next section, health care studies in

which tools were developed and tested to measure family functioning will be discussed.

### Measurement of Family Functioning

In the administration of health care there is a need to assess both the functioning of the family and that of the individual. This is so because the health of the family as a functioning unit and the health of the individuals are assumed to be interdependent (Mechanic, 1962). To establish measures of family functioning it has been necessary to identify the component parts that make-up family functioning. This portion of the literature review will look at research that was concerned with the development and testing of family functioning instruments.

The earliest study reviewed was that by Geismar associates (1962) who attempted to devise a technique to measure family disorganization that did not rest solely on demographic data. In the study, family functioning was defined by role performance of family members in nine categories: (1) family relationships and family unity including marital, parent-child, and sibling relationships as well as family solidarity; (2) individual behavior and adjustment, including the roles of husband, wife, and children as well as the mental and physical health of family members; (3) care and training of children; (4) social activities, formal and informal; (5) economic practices; (6) household practices; (7) health problems and practices;

(8) relationship to social worker; and (9) use of community resources.

On the basis of these categories of family functioning, Geismar and associates' (1961) measured family disorganization by means of rating of role performance of family members in each of the nine categories. One hundred and fifty families with multiple problems were rated on a point continuum ranging from inadequate functioning to adequate functioning, although no mention was made of the person who rated the families. On the basis of their findings Geismar and his colleagues' (1962) analysis suggest that multiproblem families have greatest difficulty with interpersonal relationships within the family, and have the least problems in the area of household practices, health conditions, and economic practices. In other words, as suggested by Geismar and associates (1962), an increased degree of incompetence in managing interpersonal relationships within the family tended to affect the family's ability to provide for adequate health, food, and shelter. Despite the usefulness of the data concerning areas to consider as components of family functioning, generated by the study, the methods used in this study were not explicit and the instrument did not prove to reliable.

Accordingly, Haggerty (1965), building on this earlier work, developed an extensive questionnaire and a

focused interview schedule to study family functioning. Haggerty's (1965) questionnaire consisted of 75 questions and covered areas such as demographic characteristics, past medical experience, and internal and external functions of the family. Included within the questions on past medical experiences of the family were several that elicited information about causes of illness in the family, use of medical and social resources, and types of preventive and therapeutic measures used. Those that dealt with internal functions of the family elicited information on relationship to family of origin, relationship of present nuclear family, stages of family life cycle, division of work in the family, in family, child-rearing practice, dominance maternal nurturing, as well as parental attitudes towards problem solving, education, religion, time orientation, and adequacy of the physical environment. Finally, the questions related to external functions of the family elicited information on social mobility and isolation, recreational activities, towards authority groups in attitude the community, occupational stress and satisfaction, and relation neighbors.

Haggerty selected 39 families of children that had been hospitalized to test his questionnaire and focused interview of family functioning. Before leaving the hospital, each parent was asked to fill out the questionnaire. Then, an identical questionnaire was sent to

the family for completion four weeks later to test the reliability of the instrument. To analyze the reliability of the instruments, Haggerty (1965) also examined agreement of response between fathers and mothers. Moreover, he had a nurse, who knew the family, rate them on a separate questionnaire. A comparison of the these three data standard sets of revealed that demographic characteristics showed 88-96 percent agreement between the different methods of obtaining data and the observers. However, there was an larger degree of variation between responses about past medical experience, internal functions of family, and external functions among the different respondents. In short, Haggerty's resulted in the identification of family functioning similar to those of Geismar and associates (1962).childrearing and nurturing, and social activites. But, just as Geismer (1962), Haggerty (1965) too was not successful in his attempt to develop a reliable instrument to measure family functioning.

Thus, the effort to develop such an instrument was continued by Pless and Satterwhite (1973) who realized that too often many potentially important items of information about the family are not sought or not recorded by the health care provider, despite the fact that family functioning is inextricably entwined with the health of the individual. For example, according to the authors, the

knowledge of a family's interpersonal relationships (i.e., family functioning) may enable the health care provider to appreciate more fully the significance of symptoms, to make her/his recommendation for treatment more realistic, or enable her/him to identify high risk situations promptly.

For the purpose of their research on the adjustment of families of children with chronic physical illness, Pless and Satterwhite (1973) defined family functioning as the dynamics of everyday life: the way in which the family, a unit, operates across several dimensions. Based on this definition they developed a family functioning index that included questions dealing with intrafamily communications, cohesiveness, decision-making, marital satisfaction, and a general assessment of the level of happiness and closeness of the family unit. In addition their instrument designed to assess the psychological adjustment of all children, sick and well. The index was administered to the parents of 399 school age children. Two hundred and nine of these children had chronic disorders and one hundred ninety were healthy.

The results of their analysis showed that the total index score was not affected significantly by the severity of the child's physical handicap and, therefore, the authors believe the index can be used with families with healthy children as well as those with chronic disorders. In addition, analysis, based on a comparison of index scores

with rating of the same families by experienced social workers, showed the family functioning index to be valid. Moreover, the high correlation (0.72) found between the scores of the husband and wife concerning each one's view of her/his family functioning demonstrated the reliability of the index. Pless and Satterwhite (1973) viewed the husband-wife comparison as a special example of test-retest reliability and considered it to be a more rigid criterion of reliability.

On the basis of their finds, Pless and Satterwhite (1973) concluded the instrument would identify chronically ill children who were likely to experience secondary psychological difficulties. Moreover, they believe the instrument is a good tool to acquire knowledge of family life that may influence health behavior since it is easily administered in the clinical setting. Despite these claims to its utility, however, the instrument does have limitations, i.e., it is geared towards families with young children.

The research for an instrument to measure family functioning has been continued by Smilkstein (1978) who defined family functioning as that behavior which promotes emotional and physical growth and maturation of all members. His Family APGAR represents the most recent attempt to develop a practical instrument to assess family functioning and is a brief screening questionnaire designed to elicit a

data base that reflects the patient's view of the functional state of her/his family.

Smilkstein used the acronym APGAR to outline the five components which appear to represent the most common themes in the literature that deal with family functioning. brief these are: Adaptation, Partnership, Growth, Affection, and Resolve. Adaptation refers to the family's ability to utilize intra and extrafamilial resources for problem-solving when family equilibrium is stressed during a the sharing crisis. Partnership pertains to of decision-making and nurturing responsibilities by the family Growth refers to the physical and emotional members. maturation and self-fulfillment that is achieved by family members through mutual support and guidance. Affection is the caring or loving relationship that exists among family members. Resolve pertains to the commitment to devote time to other members of the family for physical and emotional nurturing and the sharing of money and space as well. The questionnaire designed by Smilkstein measures family members' satisfaction with each of the five basic components of family functioning and identifies problem areas within the family unit of both nuclear and alternative life-style families.

The Family APGAR Index has been tested by Good and her associates (1979) for construct validity. In their study, Good and her colleagues (1979) administered the

questionnaire to a total of 33 subjects from two sample groups: one nonclinical group of "normal families" and one clinical group of psychiatric outpatients. In addition, they administered the Family Functioning Index (FFI) developed by Pless and Satterwhite (1973), for which validity and reliability was already established, to the two groups. And finally, they had clinical therapists rate "low functioning families" after having met with these patients on the average of 5.5 times the preceding year.

To analyze the three sets of data, Good and her associates (1979) used the comparative method. They found that the Family APGAR scores showed a strong correlation of .80 with the FFI scores. By contrast, they found only a correlation of .64 between the Family APGAR Index score and the therapists' family evaluation score and a moderate correlation of .67 between interspouse scores.

On the basis of their findings, Good and associates (1979) concluded that, the Family APGAR is an appropriate tool for health care providers to use in screening their clients for family difficulties that may affect their health behaviors. In addition, they suggested that the tool may be a useful instrument for research. However, since to date the tool only has been used with young, student families the authors suggested that the instrument should be further tested on other types of family units. That is, the usefulness of the instrument for families in different

stages of the life cycle is yet to be tested. Despite the lack of empirical data to support its utility across the developmental span of the family, the Family APGAR Index has several advantages that indicate it may be a useful research tool. That is, it is short and easy to score and, furthermore, applicable to both nuclear and alternative life-style families.

In summary, attempts to develop instruments that can be used to assess family functioning have been reviewed. Geismar and associates' (1962) instrument was neither explicit nor reliable. Haggerty's (1965) instrument was too extensive for clinical use and did not show reliability. Pless and Satterwhite's (1973) Family Functioning Index showed validity and reliability, and was easily administered in the clinical setting. But, this instrument was designed for use with families in which there are children.

In contrast, Smilkstein's (1978) Family APGAR Index, which showed reliability and validity, is short, easy to score, contains clear and concise definitions of family functioning components, and is applicable to the situation of both nuclear and alternative life-style families. Moreover, the components included in Smilkstein's index essentially encompasses other authors' concepts of family functioning. Nevertheless, Smilkstein's tool does have limitations. First, the applicability of the index for families in different stages of the life cycle has yet to be

tested. In addition, the instrument is only a screening tool and would have to be expanded if used as the basis of a study instrument. Yet, it appears to be the best tool thus far developed and it is believed that it has potential, if expanded, for use in this research project.

In the next section the review of the literature will attempt to elucidate why this is so. That is, it will contain a review of studies that focus on the family's influence on compliance behavior, as well as studies that have shown a positive relationship between family functioning and compliance. In addition, in the next section these studies will be related to the five components of family functioning.

#### Family's Influence on Compliance

Although little attention has been given to family's influence on the compliance of the adult onset diabetic patient, several studies exist that have considered the family's influence on compliance behavior in general. These studies have focused on the family's influence on: (1) psychiatric patients dropping out of treatment; (2) alcohol, and smoking withdrawal programs; drug, (3) preventative programs such as family planning and physical fitness programs for prevention of heart disease; and (4) patients with chronic problems hypertension, such as arthritis, orthopedic disabilities, kidney problems, and other chronic diseases. In the following sections, several of these studies will be reviewed and related to Smilkstein's (1978) components of family functioning.

As noted above, five components are included Smilkstein's (1978) Family APGAR. The first component, adaptation, is defined as the degree to which individuals aid each other in the time of need, i.e., the ability of family members to adapt to the situation and give support. have been conducted that have assessed adaptation. For example, Litman (1966) conducted a study of 100 patients who suddenly found themselves with a severe disability and were undergoing orthopedic rehabilitation. In his study, Litman attempted to evaluate the influence of family adaptation and support on patient's acceptance of her/his condition as perceived by staff, her/his general physical state, her/his the rehabilitation potential and her/his overall motivation and performance. Reinforcement by the patient's family measured by a paper and pencil test to ascertain the degree to which the patient perceived: (1) agreement of family members; (2) cooperation; (3) concern for each others' welfare; (4) enjoyment of association; (5) affection; admiration for each other; interest, (7) or each other: and (8) confidence, and respect for satisfaction with family relationships. The perceptions of the staff were collected via a set of staff evaluation questionnaires completed by the attending physician, the physical therapist, and the occupational therapist.

Analysis of the data collected showed that 73 percent of the 58 subjects with a good response to physical rehabilitation, as perceived by the health care staff, received positive reinforcement from their families. By contrast, 77 percent of the 42 subjects with a poor response did not obtain this encouragement from their families. As a result of these findings, Litman concluded that cooperation and concern for others' welfare were especially necessary for adaptation in the time of crisis.

The second of Smilkstein's components, partnership, has been examined in two studies of compliance behavior. According to Smilkstein (1978), partnership is defined as the degree to which family members communicate with each other about matters such as medical care or This concept was included in a study by Oakes and finances. associates (1970) in which it was found that perceived family expectations were strongly related to arthritic patients' compliance with the use of a hand splint. In their study, Oakes and associates (1970) collected data from 66 rheumatoid arthritis patients by asking them questions: one asked whether their family members expected them to wear their splint and the other asked the percentage of time in the last 18 months they had worn the splint. Additionally, a family member was asked to respond independently to the question regarding the extent of time the patient used the hand rest splint.

Another study that investigated partnership conducted by Heinzelmann and Bagley (1970) among a group of sedentary middle-aged men who were at high risk for developing heart disease. In the study, participants were asked to exercise for one hour three times a week for eighteen months. In addition, prior to beginning exercise program a telephone health behavior survey was administered to potential participants. Then, once subjects had been enrolled into the study, additional data concerning their attitudes, beliefs, and behavior were obtained by interview as well as questionnaires. This additional data was obtained at 3 to 4 month intervals during the program and at the time of termination. Analysis of the data showed that those men who had wives with a positive attitude toward a physical conditioning program made the chance of compliance with the program 80 percent. By contrast, if the wife's attitude was neutral or negative, the chance of participation fell to 40 percent.

In short, both Oakes and associates (1970) and Heinzelmann and Bagley (1970) found that perceived family expectations and support resulted in increased chance of compliance. These findings suggest that verbal and /or nonverbal communication between the family members or partners have a positive influence on compliance. Moreover, since communication about matters such as health care is an

aspect of partnership and partnership is a component of family functioning, it might be expected that family functioning will affect compliance behavior.

The third component of family functioning defined by Smilkstein (1978) is growth. According to Smilkstein, (1978), growth in individuals results when family members encourage and/or accept change, and give mutual support and quidance. One example of such growth that is related to health behavior is quitting smoking since it requires a change in life habits and therefore, reflects change or growth. A study that supports this concept was conducted by West and colleagues (1977) who evaluated the effects of support upon quitting smoking. Eight volunteer subjects attended a smoking clinic which used medication and an educational program to assist patients in quitting smoking. Five years later the researcher was able to contact successfully 559 of the original 800 patients and have them complete a mailed questionnaire or a questionnaire administer via telephone. The patients were asked about their present smoking habits and those of the people with In addition, they were asked about whom they associated. the support they perceived they received from their spouses as they tried to quit. The results of the analysis showed that patients who had quit smoking were more likely than those who were still smoking to have spouses who had never smoked or had quit smoking. Moreover, two-thirds of the

quitters perceived that their spouses had provided support that made it easier for them to quit smoking. By contrast, only about one-third of the smokers perceived that they received this support.

Still another component of family functioning defined by Smilkstein (1978) is resolve which he defines as the commitment to devote time to other members of the family for physical and emotional nurturing and to share wealth and This component has been examined in a number studies and shown to influence compliance. For example, Backeland and Lundwell (1973), in a review of research literature on dropping of the treatment, found that in 19 of the 19 studies examined, social isolation and/or lack of affiliation was reported to be а major cause discontinuing treatment in psychiatric patients. That is, patients social isolated and/or who lacked affiliation with anyone, were void of the influence of family functioning either positively or negatively. Those in social isolation lack support from family members for physical and emotional nurturing.

The last component of Smilktein's (1978) to be discussed is affection which he defined as emotional support and caring. All of the above studies suggest that emotional support and caring from other family members is conducive to compliance behavior. In addition, several studies have been conducted that have explored the relationship of social

support and/or family support to compliance behavior. For example, Caplan and associates (1976) who defined social support as encouragement provided by another person or group (friend, family acquaintence, health care provider) which the person toward a goal, studied a group moves hypertensive patients to identify factors which determine why patients do not adhere to their regimens. The findings of their study confirmed the influence on compliance behavior of the patient's perception of support from family members, especially the spouse, as well as support from the health care provider. The findings showed, however, that social support from other sources, such as best friends, was not related to compliance behavior.

However, the findings were not supported in a later study conducted by Ferguson and Boles (1979) which showed that family support did not routinely produce compliance In their study, Ferguson and Boles (1979) behavior. questioned 40 patients with arthritis to determine relationship between family support, health beliefs compliance with taking aspirin and following an exercise program. They found that the presence of family support and understanding as perceived by the patient did not routinely that authors suggest produce compliance. The unexpected finding may be due to the fact that the overall families small. And nonsupportive was number of furthermore, the family groups were stable (as measured by

patient report and investigators' clinical impression).

In summary, the majority of studies reviewed showed a positive association between specific aspects of family functioning and compliance behavior. Nevertheless, none investigated the total concept of family functioning as it relates to compliance behavior. Only one study was located that has examined these two concepts conjointly. This lone study, by Steidl and colleagues (1980), investigated the adherence to treatment and family functioning of patients receiving long-term kidney dialysis treatment. In the study, family functioning was assessed by experienced family therapists. An analysis of the data revealed no significant relationship was found between family functioning and compliance behavior in the kidney dialysis patient. However, Steidl and colleagues did find a relationship between compliance and family functioning for those patients in which family members: (1) exhibit respectful, shared adult leadership and parental coalitions (partnership); have the ability to take responsibility and have an open responsive attitude towards the opinions of others (growth); and (3) effective problem-solving demonstrate skills (adaptation).

In summary, the majority of studies reviewed showed a positive association between family influence and compliance behavior. Moreover, in several studies certain components of family functioning were shown to influence

compliance behavior. Only one study reviewed, however, investigated the total concept of family functioning as it relates to compliance behavior. And, in that study, family functioning was based on the perception of a family therapist rather than on the perception of the patient. To date then, neither the relationship between perceived family functioning and compliance behavior nor the relationship between perceived family functioning and perceived compliance behavior in the adult onset diabetic patient has been studied.

#### Summary

In this chapter one dimension of the literature reviewed related to compliance behavior. It was found that the majority of studies showed little or no association between demographic variables and compliance levels when each variable is independently examined. In addition, those studies that had investigated the relationship knowledge of the disease and regimen and compliance behavior conflicting results. Furthermore, studies disease features such as diagnosis, severity of disease, and degree of disability showed that these variables apparently have little or no association with compliance behavior. However, studies designed to examine features of the regimen, such as duration of treatment, complexity and type of regimen all found that the nature of the treatment regimen affects adherence to a regimen. That is, the longer

the duration of treatment and the more complex the regimen the less likely the patient is to comply with it.

The research reviewed also indicated that several approaches have been employed to measure compliance behavior, i.e., direct observation, physicians report, clinical outcomes, and patient self-report. Each of these approaches have their limitations, eg., clinical outcomes are affected by other things such as infection, metabolism, and stress as well as compliance behavior. Futhermore, the literature review suggests that it is difficult to identify appropriate outcome measures that indicate diabetic control. However, research has shown a relationship between perceived (self-reported) and actual compliance behavior exists.

In addition, the literature reviewed revealed that patients have more difficulty in compliance when the illness is chronic than when it is acute. Since diabetes, a chronic illness that requires extensive behavioral changes is the focus of this study, only investigations in which diabetics were studied were reviewed. This review showed that only a tenuous relationship exists between knowledge of the disease and its regimens and diabetic control. That is, only one study reported a relationship between knowledge and compliance behavior and this finding was based on measures of direct observation and self-report.

Finally, literature was reviewed on the measurement of family functioning and the family's influence on

compliance behavior. It was found that only a limited number of instruments have been developed to measure family functioning. Moreover, almost all of these instruments had limitations, e.g., not reliable, too long, geared towards families with young children. Although there are instruments to measure family functioning several studies did assess the family's influence on compliance behavior. The majority of studies did show that a positive association between family support and compliance behavior exists. addition, the results of these studies showed that certain aspects of family functioning appear to be related to compliance. Only one study, however, viewed the total concept of family functioning as it relates to adherence to a regimen. Furthermore, no studies were located that viewed the total concept of perceived family functioning as it relates to perceived compliance behavior in the adult onset diabetic.

In short, the review of the literature showed that (1) perceived compliance behavior may be an effacious measure of actual compliance behavior; and (2) a need exists to study the relationship between compliance behavior and the basic unit of living with which the patients' health is inextricably entwined. In Chapter IV the methodology and procedures used in the study to answer this need will be presented.

#### CHAPTER IV

#### METHODOLOGY AND PROCEDURE

#### Overview

This descriptive study was designed to identify the between perceived family functioning relationship and perceived compliance behavior with selected aspects of prescribed therapeutic regimen among ambulatory adult onset diabetic patients. The research design used for a study of this nature is the correlational design which determines the extent of relationship between existing variables. It interest-permits the free variation of both variables of family functioning and perceived perceived compliance behavior. Neither variable was manipulated by the researcher.

The questionnaire developed for the study consisted of three parts. The first part was used to obtain descriptive data (Appendix A). The second part of the questionnaire measured the variable perceived functioning (Appendix B) and was correlated, by means Pearson Product-Moment Correlation, with the third part of the questionnaire which measured the variable perceived compliance behavior (Appendix C). The population was a convenience sample of 25 subjects. The subjects were referred by private physicians in Flint, Michigan.

# Operational Definitions of the Variables Perceived Family Functioning

The variable, perceived family functioning, reflected by the score on the family functioning section of the questionnaire (Appendix B, items 1-26). The family functioning section of the questionnaire was developed by the researcher and was based on Smilkstein's definition of family functioning. To provide a better understanding of the variable family functioning, definition of family was included. Smilkstein (1978) defined family as a group consisting of the patient and one or more persons, children or adults, in which there is a commitment for members to nurture each other. This definition encompasses all types of families. Smilkstein (1978) further defined family functioning as that behavior which promotes emotional and physical growth and maturation of all members. Smilkstein (1978) established parameters by which a family's functional health could be measured by five basic selecting components of family function--adaptation, partnership, growth, affection, and resolve. Following is a definition of each component and the questions used to measure each component:

Adaptation is the utilization of intra and extrafamilial resources for problem solving when family equilibrium is stressed during a crisis. Adaptation was measured by questions 1, 7, 12, 16,

22 (Appendix B). The questions focus on giving and receiving help in times of need.

Partnership is the sharing of decision-making and nurturing responsibilities by family members. Partnership was measured by questions 3, 8, 14, 21, 23 (Appendix B). The questions focus on expressing opinions, discussing problems, sharing responsibilities, and sharing common interests.

Growth is the physical and emotional maturation and self-fulfillment that is achieved by family members through support and guidance. Growth was measured by questions 4, 6, 9, 19, 20, 24 (Appendix B.) The questions focus on encouraging independence and accepting changes within the family unit.

Affection is the caring or loving relationship that exists among family members. Affection was measured by questions 10, 11, 13, 17, 25 (Appendix B). The questions focus on expressing emotions i.e., love and anger and the feeling that other family members care.

Resolve is the commitment to devote time to other members of the family for physical and emotional nurturing. Resolve was measured by questions 2, 5, 15, 18, 26 (Appendix B). The questions focus on working together, spending time together, and sharing space and money.

The family functioning section of the questionnaire was developed to measure the adult onset diabetic's perception of the interactions within her/his family. Perception was defined as the individual's image of reality (King, 1979). The score on the family functioning section of the questionnaire will give an estimate of how the individual views her/his family functioning. Items were worded in a way to measure the diabetic's perception (e.g., My family spends time together for family activities).

# Perceived Compliance Behavior

The variable, perceived compliance behavior with selected aspects of the therapeutic regimen of the adult onset diabetic, was reflected by the score on the compliance section of the questionnaire (Appendix C, items 1-24). Compliance behavior is defined as the extent to which the patient perceives her/his behavior coincides with medical or health advice (Haynes et al., 1979).

The compliance behavior section of the questionnaire was designed to measure the adult onset diabetic's perception of compliance with selected aspects of the therapeutic regimen. Selected aspects of the therapeutic regimen are defined as diet, medications (insulin or oral hypoglycemics), and follow-up appointments. For diet and medication, the subjects were asked to estimate their compliance behavior within the two week period prior to filling out the questionnaire and within a six month period

of time for follow-up appointments. Following is a description of each dimension and the questions used to measure each:

<u>Diet</u> includes adherence to general principles such as eating the recommended foods in the recommended amounts, at the appropriate times, and attempting to lose or control weight. Perceived compliance with diet was measured by items 1, 3, 4, 6, 7, 9, 12, 15 (Appendix C).

Medications (insulin or oral hypoglycemics) include taking medications in prescribed doses, at prescribed times, watching for side effects, and having prescriptions refilled. Perceived compliance with medications was measured by items 2, 5, 8, 10, 11, 13, 14, 16 (Appendix C).

Follow-up appointments include keeping well and ill follow-up appointments and keeping laboratory appointments for the assessment of blood sugar. Perceived compliance with follow-up appointments were measured by items 17-24 (Appendix C).

Items were worded to determine the diabetic's perception of her/his compliance (e.g., I have followed my diet as ordered by the doctor).

#### Clinical Variables

Clinical outcome variables such as blood sugar give a fragmentary glimpse of diabetic control (Bondy & Felig 1971). Although blood sugar gives an estimate of diabetic control, blood sugar is inadequate as a measure of compliance behavior since many variables influence the blood sugar other than adherence to the diabetic regimen (Guthrie & Guthrie, 1977). Nevertheless, data concerning the blood sugar was obtained from the patient's chart to ascertain if there was a correlation between the patient's blood sugar and her/his perceived compliance behavior. A positive finding would offer veracity to the patient's self-report of compliance behavior.

The blood sugar, drawn within the month the questionnaire was completed, was obtained from the patient's record. The subject was considered within normal limits if her/his random blood sugar was between 70-120 mg/dl. Skyler and associates (1981) indicate that random blood sugar is acceptable if between 60 and 180 mg/dl although they state the 2 hour postprandial should be 150 mg/dl or less. Williams and Alling (1980) state it is desirable for the diabetic patient to maintain her/his blood sugar levels within the range of 50-150 mg/dl. For this study the random blood sugar will be considered acceptable if it is between 60-150 mg/dl. Subjects whose random blood sugar levels are

less than 60 mg or greater than 150 mg will be considered out of control.

Weight in relation to height and sex is another clinical variable that can offer veracity to a patient's report concerning compliance with diet. The height. and most recent weight of each patient was obtained from the patient's record and recorded on the chart audit sheet (Appendix D). The weight was evaluated by using Metropolitan Life Insurance height, weight chart (Capell, 1976). Weight was categorized arbitrarily into five groups: (1) weight within normal limits for height and sex; less than 20 pounds overweight; (3) 20-50 pounds overweight; (4) 51-100 pounds overweight; and (5) more than 100 pounds overweight.

# Confounding Variables

According to Haynes and his associates' (1979) extensive review of the literature, research did not reveal sufficient evidence to consider demographic characteristics as confounding variables. The confounding variables investigated in this study were: (1) number of years with diabetes; (2) number of chronic illnesses the patient had in addition to diabetes; (3) complexity of the patient's regimen; and (4) whether the patient was hospitalized for diabetes within the last six months. Complexity of the regimen was assessed by (1) number of medications; (2) number of times per day medications were taken; (3) number

of other diet restrictions; and (4) number of treatments. Information concerning the type of diabetic medication (insulin or oral hypoglycemic) prescribed for the patient was also elicited. That is, each of these confounding variables may have had an effect on the way the adult onset diabetic responded to items on the questionnaire concerning perceived compliance behavior. The confounding variables were collected by means of the confidential data sheet (Appendix A).

In summary, the major variables in this study included the adult onset diabetic's perception of her/his family functioning and the perception of her/his compliance behavior. Confounding variables included the number of years the patient had diabetes, the number of other chronic illness in addition to diabetes, complexity of regimen, and whether the patient was hospitalized for diabetes within the last six months.

## Sample

The population selected for the study was adult onset diabetics. Standard criteria used for admission into the study included the following:

- The subject was living with at least one other person since this study was concerned with family functioning. A family consists of a group consisting of the patient and one or more persons,

children or adults, in which there is a commitment for members to nurture each other (Smilkstein, 1978).

- The age at diagnosis was 30 years or older. The subjects were to have adult onset diabetes. Only rare cases of juvenile-type diabetes appear after age 30 (Cohen & Etzwiler, 1976).
- The subject was a diagnosed diabetic at least one year prior to time of selection. One year allows for a time period of adjustment to an illness (Peretz, 1970).
- The age at time of admission to the study was no more than 70 years of age and no less than 31 years of age. Thirty-one years at the time of admission allowed time for the subject to have been diagnosed for one year.
- The subjects were on a calculated diabetic diet. A calculated diabetic diet is a diet based on a prescribed number of calories that are obtained from a prescribed amount of carbohydrate, protein, and fats. Many physicians have their patients use the American Diabetic Association exchange list. The American Diabetic Association devised an exchange system where a serving constitutes an exchange and

is comprised of fixed gram weights of protein, fat, and carbohydrates. The exchange list indicates the foods allowed and the size of servings. The number of prescribed calories dictates the number allowed from each food group. exchanges physicians allow their patients to be on a "free" diet or self-chosen, unmeasured diet and tell the patients to avoid an overindulgence sweets of (Robinson, 1980). Diet is basic to all diabetic regimens. Timing of food intake, the caloric value of food ingested, and the proportions and quality of carbohydrate, fat, and protein are all important aspects of the diet (Skillman & Tzagournis, 1977).

- The subject was on an oral hypoglycemic or less than 60 units insulin per day. According to Blevins (1979), diabetics who are not controlled by diet alone are frequently placed on insulin. Blevins (1979) further states that oral hypoglycemics are used for patients who are not at risk for cardiovascular disease. Cohen and Etzwiler (1976) state that the complexity of the regimen is greater for those who are on oral hypoglycemics or insulin than those on diet alone. Researchers have found that complexity of the regimen influences compliance behavior (Haynes et al., 1979). Therefore, in an effort to keep the complexity of the regimen somewhat similar, only those on oral hypoglycemics or less than 60 units of insulin were included. Patients who require over 60 units of insulin were excluded because these patients are considered difficult to control and may have juvenile onset diabetes (Guthrie & Guthrie, 1977).

- The subject was seen at a minimum of two times per year in an ambulatory care setting for follow-up appointments for her/his diabetes. Most diabetics need to be seen at two to three month intervals for continued management, although the interval varies with the patient, the nature of the disease, and the physician (Cohen & Etzwiler, 1976).
- The subjects were able to read and complete the questionnaire since someone else reading the questionnaire to the subject may alter the way the subject answered the questions.
- Pregnant women were excluded from the study since more health care attention is given to the pregnant diabetic, thereby creating stronger motivation to comply.

To be included in the study, then, the subjects had to meet the nine criteria listed above. But, they were not excluded if either of the following variables were present.

Diabetics with other chronic illnesses were not excluded since most diabetics have other chronic illnesses (Guthrie & Guthrie, 1977). Of course, the presence of another chronic illness further increases the complexity of the regimen, thereby frequently resulting in increased noncompliance (Haynes et al. 1979). But, since it would have been difficult to obtain a sample of patients with only diabetes, subjects with multiple diseases were included. The number of other chronic illnesses was recorded on the patient data sheet (Appendix A) and was considered a confounding variable.

Diabetics who were hospitalized within the last six months for their diabetes were also included. When a patient is hospitalized due to uncontrolled diabetes the individual may receive reinforcement teaching that may serve to improve her/his compliance temporarily. The patient was asked if he/she had been hospitalized within the last six months for diabetes or if he/she had had diabetic teaching while hospitalized for another illness. Hospitalization for diabetes was considered a confounding variable (Appendix A).

In summary, the subjects included in this study were: (1) living with at least one other person; (2) diagnosed at 30 years or older; (3) diagnosed at least one year prior to the time of selection; (4) between the age of 31 and 70 years of age; (5) on a calculated diabetic diet; (6) on insulin or oral hypoglycemic; (7) seen at least two

times per year in an ambulatory care setting; (8) able to read and complete the questionnaire; and (9) not pregnant. Diabetics who had been hospitalized within the last six months and who have other chronic illnesses were not excluded. Data concerning hospitalization and other chronic illnesses were gathered per confidential data sheet (Appendix A) and were considered as confounding variables.

# Source of Sample

The subjects for this study were recruited from the practices of four private physicians in the Flint area. Three of the physicians were internists and one was a general practitioner. Two of the internists treated many diabetics. Twenty of the 25 subjects were obtained from those two offices. Four subjects were from the third internist's office and one was from the general practitioner's office.

The sample size was small and the participants represent a convenience sample. Therefore, the generalizability of the findings is limited.

## Data Collection Procedure

The researcher gained consent, verbally and in writing, from each of the four physicians (Appendix E). The researcher discussed with each of the office nurses the type of patients needed for the study and distributed to them a check list of the criteria that must be met to be admitted

to the study (Appendix F.) The nurses used the check list as a guide in selecting the diabetic patients they referred to the researcher.

As the diabetic patient came to the physician's office for her/his appointment, the nurse asked the patient if he/she would consider participating in a research project. The nurse gave the patient the introductory letter explaining the nature of the study (Appendix G) and the consent form (Appendix H). If the subject agreed, he/she was asked to sign the consent form.

The researcher contacted each physician's office every three to four days and went to their offices when the physicians had some signed consent forms from the patients who agreed to participate. The researcher collected the consent forms and obtained information from the patients' records to ascertain if each subject met the specified criteria necessary to be a participant in the In addition, a chart audit was done to gain (Appendix F). information concerning the patient's blood sugar values, dates of office visits in last six months, height, and weight. This information was placed on the chart audit sheet (Appendix D). The telephone numbers of those who met the specified criteria were obtained from the patients' records.

The researcher contacted the potential subject by telephone, identified herself, and asked the subject if

he/she had any questions concerning the research project. The researcher then arranged a time and a place for the patient to answer the questionnaire such as the patient's home, physician's office, or place of employment.

Prior to filling out the questionnaire the subject was assured of anonymity, confidentiality, and the right to The subject was requested to refuse. complete the confidential data sheet (Appendix A) and the questionnaire (Appendix B & C). The researcher was available to answer any questions the subjects had concerning the questionnaire, diabetes, or family functioning. The researcher utilized the time to review sections of the thesis in order to guard against unnecessary pressure or observation of the subject. limitation was No time placed on completing questionnaire. However, most of the subjects took ten to twenty minutes to complete it. After completion of the questionnaire, the subjects were again encouraged to ask any questions they had regarding the questionnaire, diabetes, or family functioning. A copy of the consent form with the researcher's telephone number was given to the subject in case a question should arise at a later date.

At the completion of the data collection phase, the data were coded on coding sheets and key punched to prepare for data analysis.

## **Human Rights Protection**

The measures taken to ensure that the rights of the participants were protected are presented in this section. The subjects were not solicited. All participants were informed of the purpose of the study and that participation in the study was voluntary. The participants were informed of their right to refuse participation or to withdraw from the study without it affecting the care they were presently They were assured of anonymity, receiving. by researcher explaining that there would be no name the questionnaire and that the consent form would be separated from the questionnaire. Subjects were also assured that no one from the ambulatory care setting would be permitted to read the questionnaire following its completion. The subjects were encouraged to ask questions following completion of the questionnaire.

The subjects were given a copy of the consent form which informed them of any possible adverse effects and the measures that would be provided if they experienced any of them. The researcher's name and telephone number were on the consent form enabling the subjects to withdraw from the study or ask questions that may have been stimulated by the study. Precautions were taken to ensure the rights of the participants.

#### The Instrument

The questionnaire utilized for this study contained Part A of the questionnaire contained questions two parts. concerning perceived family functioning and part B included questions concerning perceived compliance behavior. parts were developed by the researcher based on a review the literature and from the operational definitions perceived family functioning and perceived compliance The instrument was administered to three adult behavior. onset diabetic patients who met the specified criteria. The questionnaire took 10-20 minutes to complete. of the questionnaire, the completion patients were interviewed to ascertain any difficulties they may have with understanding the directions or the questions asked. None of the patients expressed any difficulty. Since it was not necessary to alter any questions, the data collected pretests were used in all analyses. In this section the development, scoring, reliability, and validity of the instrument is presented.

# Perceived Family Functioning

A review of the literature revealed that several attempts have been made to establish instruments that would measure the quality of family life, its style, or level of family functioning (Geismar, 1962; Haggerty, 1965; Pless and Satterwhite, 1973; Smilkstein, 1978). The most recent attempt was Smilkstein's Family APGAR Index (Adaptation,

Partnership, Growth, Affection, Resolve), a screening tool designed to elicit a reflection of the patient's view of her/his family functioning. Smilkstein's (1978) definition of concepts, examples of questions on the questionnaire, and the scoring were made explicit in his published article.

Previously the family APGAR has been tested primarily on younger families. The researcher believes that the components of the family APGAR (adaptation, partnership, growth, affection, and resolve) are applicable to all stages of development of the adult if the individual lives within a family unit. This is because throughout a persons life-time one needs to be able to adapt in the time of crisis, give and receive support and guidance, share in decision-making and household responsibilities, give and receive affection, and feel a sense of belongingness.

Good and associates (1979) showed the Family APGAR to have construct validity by comparing the instrument's score with the scores of an established family functioning test (Pless and Satterwhite's Family Functioning Index, 1973) and the scores of clinical therapists. There was a strong correlation of .80 between the Family APGAR Index score and the Family Functioning Index and a moderate correlation of .64 between the Family APGAR Index score and the clinical therapists' score.

Smilkstein's definition of family was considered appropriate to this study since his definition included the

nuclear family as well as alternative life-style families. The concepts used in the Family APGAR represented the common social science literature dealing with themes in the of families. The family functioning section questionnaire was developed by the researcher for this study following a review of the literature. The questions Smilkstein's (1978)constructed were based on work concerning the definitions of the components of functioning and the open-ended questions used by Smilkstein to elicit family functioning information (Appendix I). Refinement of the questions followed the evaluation by thesis committee members. Changes were made in wording and arrangement of items on the questionnaire.

The family functioning section of the questionnaire contained five to six items concerning each component of family functioning with a total of twenty-six questions. The questionnaire was in the form of an opinion scale so there were no right or wrong answers. Some statements were stated positively and some negatively. The statements were answered according to a five point Likert scale.

Each subject was asked to indicate the degree to which he/she agreed with each statement made-- strongly agree, agree, undecided, disagree, strongly disagree. Statements stated positively (Items 1, 2, 4, 6, 11, 14, 17, 18, 20, 21, 22, 25, 26 Appendix B) were rated as strongly agree - 5 points, agree - 4 points, undecided - 3 points,

disagree - 2 points, and strongly disagree - 1 point. The negatively stated statements (Items 3, 5, 7, 8, 9, 10, 12, 13, 15, 16, 19, 23, 24 Appendix B) were scored in the reverse. For example, the positive statement, "My family accepts my wishes to take on new activites", was scored five points if answered "strongly agree". The negatively stated item, "My family gets upset when I spend time away from home" was scored one point if answered "strongly agree". The higher the score, the more positive the family functioning was perceived.

Although the parameter that measures perceived family functioning was divided into five components (adaptation, partnership, growth, affection, resolve), only the total score was used for statistical purposes. This was done because the purpose of this study was to evaluate the total concept of perceived family functioning as it related to perceived compliance behavior. However, the raw scores of the components were viewed separately to ascertain if there was a marked difference in the way the subjects viewed each component.

# Perceived Compliance Behavior

Examples of compliance instruments for the diabetic patient were sought through a review of the literature. Although several studies have been conducted to evaluate compliance behavior of the diabetic (Tagliacozzo, 1974; Williams, 1967; Watkins, 1967; Hulka, 1975), few examples

of instruments were available and they were not applicable. Consequently, the researcher developed the questionnaire based on selected clinical prescriptions for the adult onset diabetic.

The dimensions of the clinical prescription that were considered for this study were compliance with diet and medication (insulin or oral hypoglycemics) within the past two weeks, and compliance with follow-up appointments during the last six months. Questions concerning other aspects of the regimen such as urine testing, exercise, and general hygiene including foot care were excluded. The reason for exclusion is that patients are not usually given a written prescription regarding urine testing, exercise, and general hygiene. These aspects of the regimen are frequently not recommended and/or taught with equal emphasis by all health care providers.

questionnaire Refinement of the followed the evaluation of the questionnaire by thesis committee members. Statements were changed to increase the clarity of some items. Changes in the arrangement of items on the made so a definite pattern questionnaire were also of positive and negative statements would not be apparent. In addition, the questions concerning follow-up appointments were separated from the questions concerning diet and medication because of the difference in time frame to be considered.

The perceived compliance behavior section of the questionnaire contained eight items concerning each dimension of the therapeutic regimen (diet, medication, and follow-up appointments) with a total of twenty-four questions. The questions were stated positively and negatively and were scored according to a five point Likert scale.

Each subject was asked to select the most appropriate category representing the extent to which he/she had perceived herself/himself as complying with what the statement indicated. The subject was to consider the past two weeks for diet and medication statements and the past six months for follow-up appointment statements. The choices included the following: never, seldom, half of the time, most of the time, all of the time. These categories selected to indicate the degree of perceived compliance. Negative statements (Items 1, 2, 3, 6, 7, 8, 10, 11, 15, 17, 19, 22, 23 Appendix C) were rated as never -5 points, seldom - 4 points, half of the time - 3 points, most of the time - 2 points, all of the time - 1 point. Positive statements (Items 4, 5, 9, 12, 13, 14, 16, 18, 20, 21, 24 Appendix C) were scored in the reverse. For example, the positive statement, "I have taken my medicine in the amounts ordered", if answered "all of the time" was scored five points. In contrast, the negative statement, "I have eaten snacks that are not on my diet", when answered "all of the time" was scored one point. Again, a high score would indicate high perceived compliance behavior. Perceived compliance behavior was measured by the total score and the total score was used to ascertain if there was a statistically significant relationship between perceived family functioning and perceived compliance behavior. However, the raw scores of each dimension (diet, medication, follow-up appointments) were viewed independently as well. According to Marston (1970), a more precise answer can be given regarding compliance behavior by looking at the dimensions individually.

# Reliability

The reliability of an instrument is the degree of consistency with which it measures the attribute it is supposed to be measuring (Ary et al., 1972). The procedure used to estimate reliability for this study was the coefficient alpha. The coefficient alpha is a mathematical method which determines how all items on the questionnaire relate to all other items as well as how the items relate to the questionnaire as a whole. This refers to the internal consistency or inter-item relatedness.

Crano and Brewer (1973) state coefficient alpha probably represents the best estimate of internal consistency because it is free from all the other influences on reliability that are common to other means of testing reliability. For example, the test-retest method

necessitates access to the same subjects at a later The time lag between the test-retest method may result in subjects answering the questions differently due to other intervening events that may have occurred during the time lag. The intervening event may be a death, a crisis within the family, or other event that may have changed individual's attitudes, behaviors, moods, or knowledge. The low correlation that may be obtained may be due to change that has taken place in the individual rather than the unreliability of the test. Another test of reliability is the split-half method. However, the split-half method tends to underestimate the reliability of the questionnaire since longer questionnaires are more reliable than shorter ones (Crano and Brewer, 1973).

For this study it is necessary that a high degree of interrelatedness exists among all items so the items can be summed together to produce an overall score that is a meaningful measurement of the total concept of perceived family functioning or perceived compliance behavior. total items in the family functioning section of questionnaire will be evaluated as well as the total items in the compliance section. If the coefficient alpha is .80 or above then it is a satisfactory criterion of internal the basic requirement for consistency and fulfills operationalization of the concept (Crano and Brewer, 1973). If the scale does not meet this criterion of .80, the

researcher must identify the items with a low and/or negative correlation and delete them from the pool of items.

# **Validity**

The only level of validity possible to this study is content validity. Content validity refers to the degree to which an instrument samples the content area which is to be measured (Ary et al., 1972). That is, how well do the items in the questionnaire represent the multitude of all that might be asked? Content validity is based on judgment of experts. The researcher reviewed the family functioning and compliance literature to obtain material feasible for item construction. Following the development of the items by the researcher, the items were evaluated based upon the expert judgment of thesis committee members. Further refinement of the instrument occurred following the evaluation by thesis committee members. Changes were made in wording and arrangement of items on the questionnaire. The instrument was then assumed to be reflective of content validity.

Two threats to validity were considered when constructing the questionnaire. One threat to validity is acquiescence. That is, some individuals tend to agree with positive statements. To minimize the threat to validity both positive and negative statements were included. The second threat to validity is social desirability. That is,

soi th as some individuals tend to answer questions in the way they think the researcher expects they should. To decrease this threat to validity, the researcher asked the subjects to be as honest as possible and assured them of anonymity.

In summary, this section has included a discussion of the instrument in terms of its development and scoring, reliability and validity. In the next section the research question, hypothesis, subresearch questions, and techniques used for data analysis will be presented.

# Research Ouestion, Hypothesis, and Subresearch Ouestions

The research question was stated as follows:

Is there a relationship between the perceived family functioning and the perceived compliance behavior with selected aspects of the prescribed therapeutic regimen of ambulatory adult onset diabetic patients?

The following hypothesis was tested in this study:

There is a relationship between the perceived family functioning and the perceived compliance behavior with selected aspects of the prescribed therapeutic regimen of ambulatory adult onset diabetic patients.

Two subresearch questions were asked. They are as follows:

- 1. How does the ambulatory adult onset diabetic perceive her/his family functioning?
- 2. How does the ambulatory adult onset diabetic perceive her/his compliance with the therapeutic regimen?

These questions were analyzed according to statistical techniques suitable for descriptive data.

The research questions were answered by analyzing the raw scores of perceived family functioning and perceived compliance behavior using the Pearson Product-Moment Correlation coefficient (Pearson r). The Pearson r is the most commonly used correlational index for descriptive studies. The Pearson r enables the researcher to make an association but does not necessarily indicate a causal relationship.

If the two variables, perceived family functioning and perceived compliance behavior, were highly related in a positive way the correlation between them would approach +1. If they were highly related in a negative way the correlation would approach -1. If there was little relation between them the correlation would be near zero. The difference between the coefficient and zero indicated the degree of relationship. The interpretation of r computed between the variables in this study was:

- 1.  $\underline{r}$  from 0.00 to 0.15 or 0.20 represented negligible, or if close to 0.20, very slight relationship between the variables.
- r from 0.20 to 0.40 represented low correlation present, but slight.
- 3. <u>r</u> from 0.40 to 0.60 represented moderate or fair correlation.

- 4. r from 0.60 to 0.80 represented marked, somewhat high relationship.
- 5. <u>r</u> from 0.80 to 1.00 represented high to very high relationship (VanOrmer and Williams 1949, p. 65).

When a correlation coefficient is derived, the statistical significance indicates whether or not the coeefficient obtained is different from zero at a given level of confidence. A statistically significant correlation represents evidence of an actual relationship rather than one due simply to chance. The level of significance for this study was set at .05. The .05 level is the level of significance commonly used when product moment correlation is used and when the sample size is small.

The subresearch questions were answered according to descriptive statistics also. The range and median were calculated for each section of the questionnaire to answer the questions.

In summary, in this section the research question, hypothesis, subresearch questions, and techniques used for data analysis were presented.

## Summary

In Chapter IV an overview of the methodology and procedures involved in the study was presented. The discussion included a presentation of the operational definitions of the variables, sample, source of sample, data

collection procedures, human right protection, instrument, and hypothesis and research questions. The data will be presented in Chapter V.

## Chapter V

#### DATA PRESENTATION AND ANALYSIS

## Overview

The data presented in this chapter describe the study population and answer the following research question:

Is there a relationship between the perceived family functioning and the perceived compliance with selected aspects of the prescribed therapeutic regimen of ambulatory adult onset diabetic patients?

In addition, data are presented to explain the relationship between the confounding variables (i.e., number of years with diabetes, number of chronic illnesses other than diabetes, complexity of regimen, and hospitalization within the last six months) and their effect on compliance behavior. Also included in this chapter is an analysis of the reliability of the perceived family functioning and compliance questionnaire. The hypothesis and the subresearch questions that are presented and analyzed are:

#### Hypothesis

There is a relationship between the perceived family functioning and the perceived compliance with selected aspects of the prescribed therapeutic regimen of ambulatory adult onset diabetic patients.

# Subresearch Ouestions

- 1. How does the ambulatory adult onset diabetic perceive her/his family functioning?
- 2. How does the ambulatory adult onset diabetic perceive her/his compliance with the therapeutic regimen?

# Descriptive Findings of the Study Sample

The sample was drawn from the population of diabetic patients who sought care from four private physicians Michigan. The study sample consisted Flint. ambulatory adult onset diabetics who ranged in age from 36 to 70 years old with a mean age of 52.5 years. Nine of the subjects (36%) were 36 to 47 years of age, nine (36%) were 48 to 59, and seven (28%) were 60 to 70 years of age. Thirteen males (52%) and 12 females (48%) participated this study. Almost all were white (96%); only one subject (4%) was black. The annual family income of subjects ranged from less than \$10,000 to greater than \$20,000 per year. Two subjects (8%) had incomes of less than \$10,000, seven (28%) had incomes of \$10,000 to \$19,999, and 16 (64%) incomes of \$20,000 or greater. Data on age sex, race, and income are summarized in Table 1.

Three (12%) subjects in the study were single, twenty-one (84%) were married and one (4%) was separated. The number of people with whom the subjects lived ranged from one to seven. A majority (56%) lived with one other person only. Approximately half (48%) of the subjects had

TABLE 1. Sociodemographic Data by Age, Sex, Race. and Income of Participants (n = 25).

	Number of Participants	Percent
Age		
36 to 47	9	36
48 to 59	9	36
60 to 70	7	28
Total	25	100
Sex		
Male	13	52
Female	12	48
Total	25	100
Race		
Black	1	4
White	24	96
Total	25	100
Income		
Less than 10,000/year	2	8
\$10,000 - \$19,999/year	7	28
\$20,000 or greater/year	16	64
Total	25	100

children living with them. The number of children in the families ranged from one to six. These children's ages ranged from two to thirty-two years of age with a mean of

sixteen years and a median of eighteen years. All but one of these subjects with children was living within a nuclear unit. The one exception was a woman who was separated from her husband and who lived with her child. Thus, the composition of the household varied among the 25 participants. See Table 2 for the summary of these data.

TABLE 2. Living Arrangements of Participants (n = 25).

Living Arrangements	Number of Participants	Percent
Live with spouse	10	40
Live with spouse and unmarried children	11	44
Live with either sibling, cousin, or child	4	16
Total	25	100

The number of years the participants had diabetes ranged from one to more than twenty years. Eleven subjects (44%) had diabetes one to five years, nine (36%) from six to ten years, two (8%) from eleven to fifteen years, one (4%) from sixteen to twenty years, and two (8%) subjects had diabetes more than twenty years.

To be a participant in the study the subjects had to have had either an oral hypoglycemic or insulin prescribed for their diabetes. Fifteen (60%) of the subjects were taking insulin and ten (40%) were taking oral hypoglycemics.

One-fifth (20%) of the patients had diabetes only (see Table 3). In addition to diabetes, of the twenty patients who had other chronic diseases, twelve (60%) had one other illness, five (25%) had two other illnesses, and three (15%) had three other illnesses. The most frequent other chronic illness mentioned by the twenty subjects was hypertension (60%). This disease was followed in frequency by heart problems (16%) and arthritis (16%). In total, the twenty subjects with other chronic diseases mentioned eight maladies. These data are summarized in Table 4.

As might be expected then, the complexity of the regimen that had been prescribed for the patients varied. For example, seventeen (68%) of the subjects were taking medications in addition to those prescribed for their diabetes. The number of these other medications ranged from one to five (Table 5). Seven of the seventeen patients (41%) were on one other medication, three (18%) were on two other medications, three (18%) were on three other medications, three (18%) were on four other medication, and one (6%) was on five other medications.

The number of times per day the subjects were taking medication ranged from one time to four times. Seven (28%) of the subjects were taking medication once a day, ten (40%) two times per day, four (16%) three times per day, and four (16%) four times per day (Table 6).

Sixteen (64%) of the subjects indicated that no other diet restrictions had been prescribed for them other than their diabetic diet (Table 7).

TABLE 3. Number of Chronic Illnesses of Participants (n = 25).

Number of Chronic Illnesses Besides Diabetes	Number of Participants	Percent
0	5	20
1	12	48
2	5	20
3	3	12
Tot	al <u>25</u>	100

TABLE 4. Types of other Chronic Illnesses of Participants.

Illnesses	Number of Participants	Percent
Hypertension	15	60
Heart Problems	4	16
Peripheral Vascular Disease	2	8
Arthritis	4	16
Asthma	1	4
Kidney Disease	1	4
Thyroid Disease	2	8
Female Problems	2	8

TABLE 5. Complexity of Regimen Measured by Number of Medications Other than Medication for Diabetes.

Number of Other Medications	Number of Participants	Percent
0	8	32
1	7	28
2	3	12
3	3	12
4	3	12
5	1	4
Total	25	100

TABLE 6. Complexity of Regimen Measured by Number of Times per Day Taking Medication

Number of Times per Day Taking Medication	Number of Participants	Percent
1	7	28
2	10	40
3	4	16
4	4	16
Total	25	100

TABLE 7. Complexity of Regimen Measured by Number of Diet Restrictions Other than the Diabetic Diet.

Number of Other Diet Restrictions	Number of Participants	Percent
0	16	64
1	7	28
2	2	8
Total	25	100

Among the nine subjects who had been told to follow a diet in addition to that prescribed for their diabetes, six subjects (67%) were on low salt diets, two (22%) were on low salt and low cholesterol diets, and one (11%) was on a low cholesterol diet.

Besides additional medications and diet restrictions for the other chronic illnesses, only three subjects (12%) mentioned that they had been told to exercise for their heart problem. Twenty-two (88%) mentioned no treatments other than what was prescribed for their diabetes.

Only one (4%) of the 25 subjects was hospitalized for diabetes in the last six months and had had diabetic teaching. Subjects who were hospitalized for other reasons in the last six months denied having had any diabetic teaching while hospitalized.

# Reliability of Instrument

To determine the inter-item relatedness of items within the questionnaire, the reliability of the instrument was measured by computing coefficient alpha. Two coefficient alphas were calculated: one for the perceived family functioning section of the questionnaire and one for the perceived compliance behavior section of the questionnaire.

In the perceived family functioning section of the questionnaire, items F1, F7, F16, F19 were found to have a low inter-item correlation, i.e., below .20, and were deleted from the pool of items. Following the deletion of these items, the twenty-two items remaining in the perceived family functioning section (Appendix J) had a coefficient alpha of .84, thus demonstrating internal consistency.

In the perceived compliance behavior section of the questionnaire only two items had to be deleted. That is, items C7 and C16 were found to have a correlation below .20, and accordingly were deleted from the pool of items. Following the deletion of these items, the 22 items remaining in the perceived compliance behavior section (Appendix J) had a coefficient alpha of .88, demonstrating internal consistency.

Each of the dimensions of the therapeutic regimen (i.e., diet, medication, and follow-up appointments) was subjected to individual coefficient alpha analysis to

evaluate the interrelatedness between the items contained within them.

The reliability analysis to determine internal consistency for items concerning diet resulted in the deletion of items C4, C7, C15 since an inter-item correlation below .20 was found. Items C1, C3, C6, C9, C12, remained in the pool with a coefficient alpha of .86 which demonstrated internal consistency among the five items for diet.

Following the reliability analysis on the medication items, items C2 and C13 were deleted from the pool because of a low inter-item correlation, i.e., below .20. Items C5, C8, C10, C11, C14, C16 remained in the pool with a coefficient alpha of .73. This coefficient alpha demonstrated internal consistency among the items for medications.

The reliability analysis to determine internal consistency for items concerning follow-up appointments resulted in the deletion of items C19 and C20 from the pool of items due to a low inter-item correlation, i.e., below .20. Items C17, C18, C21, C22, C23, C24 remained in the pool with a coefficient alpha of .93. This statistic demonstrated internal consistency among the items for follow-up appointments.

# Data Presentation for Hypothesis

## The Statistical Technique

This study was a descriptive study and therefore was analyzed according to descriptive statistics. Correlation is the statistical technique used for measuring the degree of relationship between two variables which results in a value that ranges from -1 to +1. The Pearson Product-Moment Correlation (also called Pearson r) is the most commonly used correlational index for descriptive studies al., 1972). After items that correlated below .20 were to determine omitted, the Pearson r was used the relationship between the raw scores of perceived compliance behavior and perceived family functioning. For this study, to accept the hypothesis, the level of confidence was set at .05. The .05 level is the level of significance commonly used when product moment correlation is used and when the sample size is small.

#### Hypothesis

There is a relationship between the perceived family functioning and the perceived compliance with selected aspects of the prescribed therapeutic regimen of ambulatory adult onset diabetic patients.

Perceived family functioning and perceived compliance behavior were measured by statements contained within a self-administered questionnaire. Responses to statements were recorded on a five point Likert scale. Some

statements were stated positively and some were stated negatively to prevent the development of a response situation.

To test the hypothesis a Pearson Product-Moment Correlation was performed. First, a numerical value was assigned to each response that indicated the degree of agreement or disagreement with the individual statements contained in perceived family functioning section perceived compliance behavior section of the questionnaire. Then the values of the items measuring perceived family functioning and the items measuring perceived compliance behavior were summed separately. That is, each subject was assigned two scores: one score represented the value of summed perceived family functioning responses and one score the value of summed perceived compliance represented behavior responses. Finally, the sum of the raw scores of perceived family functioning was correlated with the sum of the raw scores of perceived compliance behavior.

The Pearson Product-Moment Correlation between the perceived family functioning score and the perceived compliance behavior score was r=.10 and not significant at the .05 level. Thus, there was no relationship between perceived family functioning and perceived compliance behavior.

#### Subresearch Ouestions

The data relevant to the subresearch questions also were subjected to descriptive statistic techniques. That is, the range, mean, and median were calculated for the variables dealt within the questionnaire.

Question 1: How does the ambulatory adult onset diabetic
perceive her/his family functioning?

The scores of the perceived total family functioning section showed a range of 73 to 102 with a maximum score possible of 110. The mean for the scores was 87.60, with a standard deviation of 8.26. The median was 87.00. The average score for each question was 3.98 with a range of 1 to 5. The subjects in this sample had a positive view of their family functioning.

Question 2: How does the ambulatory adult onset diabetic
perceive her/his compliance behavior?

The perceived compliance behavior scores showed a range of 76 to 105 with a possible score of 110. The mean for the scores was 96.12 with a standard deviation of 7.75 and a median of 96.00. The average score for each question was 4.36 with a range of 1 to 5. The subjects perceived themselves as complying with their therapeutic regimen more than "most of the time".

A more precise answer can be given to the subresearch question regarding compliance behavior by looking at the dimensions individually.

The scores on the perceived compliance behavior for diet showed a range of 13 to 25 with a possible of 25. The mean was 17.64 with a standard deviation of 3.20. The median was 18.25. The average score for each question was 3.52 with a range of 1 to 5.

The perceived compliance behavior for medications scores ranged from 24 to 30 with a possible score of 30 and a mean of 28.64 with a standard deviation of 1.75. The median was 29.18. The average score for each question was 4.77 with a range of 1 to 5.

The scores on the perceived compliance behavior for follow-up appointments ranged from 19 to 30 with a possible of 30 and a mean of 28.60. The average score for each question was 4.76 with a range of 1 to 5. The raw scores indicated that compliance with follow-up appointments and medication were somewhat higher than compliance with diet.

### Clinical Parameters

The clinical parameters collected for this study were (1) height, (2) weight, and (3) the most recent random blood sugar within the month the questionnaire was completed. The relationship between these variables and perceived family functioning and perceived compliance

behavior was analyzed using Pearson Product-Moment Correlations.

The evaluation of weight according to height and sex showed that the weight of only two patients (8%) was within normal limits. Four patients (16%) were less than 20 pounds overweight, eight (32%) were 20 to 50 pounds overweight, six (24%) were 51 to 100 pounds overweight, and five (20%) were more than 100 pounds overweight. The degree of obesity was not significantly related to perceived family functioning (r = .16) or to perceived compliance behavior (r = -.26). The low negative correlation between weight and perceived compliance behavior implies a reversed relationship. That is, the more overweight the patient, the lower the perceived compliance behavior score.

An examination of the random blood sugar levels drawn within the month the questionnaire was completed showed that seven levels (28%) were within normal limits (70-120 mg/ml), two (8%) were within an acceptable range (60-69 mg/ml and 121-150 mg/ml), and sixteen (64%) were in a range indicating lack of control (<60 or >150mg/ml). The blood sugar levels of the subjects were inversely related to perceived compliance behavior (r = -.01) and not significant at the .05 level. The blood sugar levels of the patients also were inversely related to perceived family functioning (r = -.32) and not significant at the .05 level. The negative correlations indicate that the higher the

individual's random blood sugar level the lower the individual's perceived compliance behavior and perceived family functioning scores.

In summary, the majority (92%) of the subjects in this sample were overweight in relation to height and sex and the majority (64%) had random sugar levels that indicated lack of control of diabetes. In addition, a significant relationship was not found between perceived family functioning or perceived compliance behavior and weight or blood sugar level.

#### Confounding Variables

The relationship between the four confounding variables and perceived family functioning and perceived compliance behavior was analyzed using Pearson Product-Moment Correlation. The four confounding variables examined were: (1) number of years with diabetes; number of other chronic illnesses; (3) complexity of the regimen (i.e., number of other medications, number of day taking medication, number diet per of other restrictions, and number of other treatments); and (4) hospitalization within the last six months.

### Confounding Variable 1

The number of years the participants had diabetes was neither related to perceived compliance behavior (r = .26) nor to perceived family functioning (r = -.16) at a

.05 level of significance. The negative correlation derived shows that as the number of years with diabetes increases, the score for perceived family functioning decreases.

### Confounding Variable 2

The number of other chronic illness the subjects had was related to perceived compliance behavior (r = -.34) at the .05 level of significance. The negative relationship between the two variables indicates that as the number of chronic illnesses increases the score of the perceived compliance behavior decreases. No significant relationship was found between the number of other chronic illnesses and perceived family functioning (r = .25).

# Confounding Variable 3a

The number of medications the patient was taking was not significantly related to perceived compliance behavior, r = -.11.

### Confounding Variable 3b

The number of times per day the patient was taking medication was not significantly related to perceived compliance behavior, r = .12.

#### Confounding Variable 3c

The number of diet restrictions was not significantly related to perceived compliance behavior, r = .16.

# Confounding Variable 3d

The number of additional treatments for other chronic illnesses was not significantly related to perceived compliance behavior, r = .12.

# Confounding Variable 4

Only one subject in the study had been hospitalized for diabetes in the six months prior to the study. Thus, insufficient data were available to compute a correlation coefficient.

In summary, the number of years with diabetes and the complexity of the regimen were not significantly related to perceived compliance behavior in this study. There was a low correlation between the number of other chronic illnesses and perceived compliance behavior, significant at the .05 level.

#### Summary

In Chapter V data were presented that described study population. Reliability analyses were performed on the perceived family functioning section and the perceived behavior of the questionnaire compliance utilizing coefficient alpha. Data were presented and the result of the Pearson Product-Moment Correlation analysis for the research hypothesis to test the relationship between family functioning and perceived compliance perceived behavior was described. Descriptive statistics (range,

mean, and median) were used to answer the subresearch questions. The Pearson r was also used to analyze a correlation of the clinical parameters with perceived family functioning and perceived compliance behavior. In addition, the Pearson r was also used to analyze a correlation of the confounding variables with perceived compliance behavior. Selected confounding variables were correlated with perceived family functioning scores as well. In chapter VI the summary, interpretation, and implications of these findings will be presented.

#### CHAPTER VI

# SUMMARY OF FINDINGS, INTERPRETATION, AND IMPLICATIONS

#### Overview

In this chapter a summary and interpretation of the research findings are discussed. Implications for nursing practice, education, and recommendations for future research are offered.

# Summary and Interpretation of Findings

# Descriptive Findings of the Study Population

The demographics of this study population include age, sex, race, and income. A criterion for participation in this study was that subjects must be at least 31 years of age. The sample ranged from 36 to 70 years old with a mean age of 52.5 years. Nine (36%) of the subjects were between thirty-six and forty-seven years of age, nine (36%) between forty-eight and fifty-nine years of age, and seven (28%) were sixty to seventy years of age. Although incidence of diabetes increases with age (Blevins, 1979; fairly Sayetta & Murphy, 1979), there was a even distribution of ages of subjects in this study. This may be due to the age limitation stated in the criteria established for inclusion in this study.

Thirteen (52%) of the twenty-five subjects were male

and twelve (48%) were female. The majority (24) of the subjects were white; only one was black. The reason for this distribution, no doubt, is that the sample was drawn from the patient population of four white physicians whose clientele is predominantly white.

The source of the subjects, undoubtly, also explains the large number of middle-class and upper middle-class patients in the sample. That is, only two subjects (8%) had an income of less than \$10,000. Sixteen (64%) had an income of greater than \$20,000 per year.

According to Blevins (1979), the incidence prevalence of diabetes are related to factors of age, sex, race, and income. That is, those people at high risk to aged, women, the poor, and the develop diabetes are the Center Health nonwhite. Data from the National for Statistics, which show that diabetes increases advancing age and occurs more frequently in females and blacks (Sayetta & Murphy, 1979), support Blevins' (1979) statement. Thus, the sample for this study was not typical relative to the incidence of diabetes by age, sex, race, and The sample's atypicality most probably is due to income. the fact that it was drawn from a population of patients who sought care at private physicians' practices.

Ninety-two percent of the subjects in this study were overweight. In addition, the majority (64%) of the subjects had random blood sugar values that indicated that

their diabetes was out of control.

A primary concern of this study is functioning and, therefore, to be included in the samples the participants had to be living with at least one other person. Although traditional definitions of the family focus on the nuclear unit, such a restricted definition not used in this study. Instead, Rakel's (1977) Smilkstein's (1978) definition of the family, encompasses people living in non-traditional units, was accepted. According to Rakel (1977) and Smilkstein (1978), a family can be viewed as two or more people who have a commitment to nurture each other and who have a significant Thus, the subjects in this study effect on one another. lived in families were conjugal that as well non-conjugal. For example, twenty-one of the subjects (84%) lived with their spouse and eleven (52%) of these subjects still had children who lived at home. By contrast, one subject was separated and lived with her eight year old son and three subjects were single. Two of these non-married subjects lived with a sibling and one with a cousin.

In summary, the subjects in this study were not typical relative to the incidence of diabetes by age, sex, race, or income. Moreover, the majority of subjects were overweight and their random blood sugar indicated their diabetes was out of control. Finally, all but three of the subjects lived in a nuclear family.

# **Hypothesis**

There is a relationship between the perceived family functioning and the perceived compliance with selected aspects of the prescribed therapeutic regimen of ambulatory adult onset diabetic patients.

family between perceived The relationship functioning and perceived compliance behavior was low ( r = .10) and not statistically significant at the .05 level. Thus, there is no relationship between perceived family functioning and perceived compliance behavior. In other words, adult onset diabetics who perceive their families as (1) aiding each other in the time of need (adaptation), (2) communicating with each other (partnership), (3) encouraging independence (growth), (4) encouraging emotional expression (affection), and (5) willing to share time, space, and money (resolve), do not perceive themselves as complying with their diabetic regimen concerning their diet, medications, and follow-up appointments.

Nevertheless, although evidence is lacking to support a relationship between perceived family functioning and perceived compliance behavior, it still cannot be said with certainty that no relationship exists between these two Several factors may have influenced variables. findings. For example, the sample size was small and a convenience sample from limited geographic areas and limited sources (i.e., the population of patients seeking care from private physicians). Therefore, the sample be cannot

considered representative of the entire population of diabetic patients. In addition, the sample was not typical of the adult onset diabetic in terms of age, sex, race, or income. That is, most of the subjects were white (96%) and had an income of greater than \$20,000 per year (64%). These factors then, may have influenced the results of this study.

Yet another factor that may have influenced the findings concerns viewing perceived family functioning in its totality rather than by individual components. Based on a review of family literature, the researcher believes the family functioning section of the instrument encompassed the major components of family functioning. The study, however, was not designed to investigate the individual components of perceived That family functioning. is, the functioning section of the questionnaire was not long enough to evaluate effectively each component separately. If each component was investigated separately, a relationship may have been found between some of the individual components of perceived family functioning and perceived compliance behavior even though it was not found for the total concept. For example, there may have been a relationship between perceived adaptation and perceived compliance behavior. Future research is needed to investigate further both the total concept of perceived family functioning and individual components of perceived family functioning as related to perceived compliance behavior.

In summary, the research hypothesis was rejected due to the nonsignificant finding. To substantiate this finding, further study would be necessary using a larger sample size and a different type of sample (i.e., clinic patients versus patients of private physicians). There is need for future research to investigate the components of family functioning separately as well as in totality.

#### Subresearch Ouestions

Question 1: How does the ambulatory adult onset diabetic perceive her/his family functioning?

A descriptive analysis of the family functioning section of the questionnaire was used to explore the degree to which patients felt their families: (1) gave support in time of need (adaptation); (2) communicated and made decisions (partnership); (3) accepted change and promoted (4) accepted and expressed emotions independence (growth); (affection); and (5) shared time, space, and (resolve). The scores for perceived family functioning ranged from 73 to 102 with a possible score of 110, thus showing little variation in response among subjects. mean score of the total index was 87.60. The average score for the questions in the perceived family functioning section of the questionnaire was 3.98 with the greatest possible score being 5. The scores indicated that in this sample, on the average, the subjects' perception of family functioning was positive. No studies reviewed reported how

a person perceives her/his family functioning, thus a comparison of results cannot be made.

The coefficient alpha for the total perceived family functioning section of the questionnaire was .84 and showed interrelatedness of the items on the total perceived family functioning section of the questionnaire. This finding, however, does not mean that the subjects perceived each of the components equally. That is, each of the components of family functioning (adaptation, partnership, growth, affection, and resolve) were not viewed separately, and therefore, it cannot be implied that the subjects perceive each of the components equally.

For example, subjects may be positive in their perception of the family's ability to give each other support in times of need, in their ability to communicate and make decisions, and in their ability to accept change and to promote independence; however, they may not feel as positive about the family's ability to give and receive affection, and/or their ability to share time, space, and money with each other. Thus, in an effort to ascertain how the subjects in this sample viewed the separate components of family functioning, the raw scores were analyzed. That is, an estimate of how, on the average, each component was viewed by the subjects was obtained. With a possible score of 5, the average score for the questions were: adaptation 3.64, partnership 3.89, growth 3.95, affection 4.01, and

resolve 4.02. The variance between the components of family functioning was only slight. For example, the subjects in this sample were almost as positive in their perception of the family's ability to give support in times of need as they were in their perception of their family's ability to share time, space, and money.

In summary, the subjects in this study, on the average, veiwed their family functioning positively. Examination of the raw scores for each component of family functioning showed, however, only slight variance between the separate components of family functioning. Further research is necessary to study the interrelationship of each component (adaptation, partnership, growth, affection, and resolve) in more detail.

# Question 2: How does the ambulatory adult onset diabetic perceive her/his compliance with the therapeutic regimen?

The subjects indicated, via the perceived compliance section of the questionnaire, the degree to which they felt they complied with the diet, medications, and follow-up appointments for diabetes prescribed by their health care providers. The scores of perceived compliance behavior ranged from 75 to 105 with a possible score of 110, again showing little variation in response among subjects. The mean score for perceived compliance behavior was 96.12. The average score for the questions on the whole was 4.36. Concerning the positively stated items "all the time" was

scored as 5, "most of the time" as 4, "half of the time" as 3, "seldom" as 2, and "never" as 1. Negatively stated items were scored in the reverse. The scores suggest that the subjects in this sample, on the average, perceive themselves to be following their diet, taking their medication, and keeping their follow-up appointments more than "most of the time".

The coefficient alpha for the total compliance behavior section of the questionnaire was .88 and showed interrelatedness of items. However, because of the possibility that the compliance score might be somewhat high due to loss of precision by combining the compliance scores concerning diet, medication, and follow-up appointments, each dimension was viewed separately.

Perceived compliance for scores follow-up appointments showed a range of 19 to 30 with a possible of 30. The mean for the group of subjects was 28.60. average score for the questions was 4.76, suggesting that the subjects perceived themselves as complying with follow-up appointments and having their blood sugar drawn almost "all of the time". An audit of the clinical records to ascertain number of appointments the patients missed in the 6 months prior to completing the questionnaire, supported this finding. That is, none of the subjects had missed appointments during the specified six-month period. In addition, all of the subjects had had a blood sugar drawn prior to or at the time of each follow-up appointment for diabetes. It appears, then, that self-reported compliance concerning keeping follow-up appointments was consistent with actual behavior. Moreover, the findings of this study support previous research which has shown that patients who experience continuity of care and receive care from private physicians tend to keep follow-up appointments (Haynes et al., 1979).

Perceived compliance behavior for taking medications ranged from 24 to 30 with a possible of 30. The mean score The average score for each question concerning was 28.64. medication was 4.47. This score suggests that the subjects in this sample perceive themselves as complying with taking medications for their diabetes midway between "most of the time" and "all of the time". An audit of the clinical record to ascertain the patients random blood sugar within the month the questionnaire was completed, did not support this finding. That is, the subjects in this sample perceive themselves as complying with taking medication very well. Yet, the majority (64%) had random blood sugar levels that indicated the patients' diabetes was not under control. (For further discussion concerning how the patient's blood sugar relates to perceived compliance behavior, see the clinical parameters section below).

All 25 subjects in this study were on a calculated diabetic diet according to their clinical records. However,

when the researcher was administering the questionnaire four of the subjects commented that they did not count calories or use the exchange list. Instead they indicated, they limited the amount they ate and avoided sweets. Such noncompliance was reflected in the scores derived on the perceived compliance behavior for diet. That is, the scores ranged from 13 to 25 with a possible of 25 and a mean score of 18.25. The average score for the diet questions was 3.52, suggesting that, on the average, the subjects perceive themselves as complying with their diet midway between "half of the time" and "most of the time".

The chart audit concerning weight, as related to height and sex, indicated that the subjects in this sample probably overestimated their compliance with following their diet. That is, 92 percent of the subjects in this sample were overweight and 44 percent were more than 50 pounds overweight. It appears, then, that higher rates of compliance may have been reported than if compliance was based on more objective measures such as weight. consistent with Haynes and his associates' (1979) findings, i.e., higher rates of compliance are reported when based on self-report by patients than when based on more objective measures such as clinical outcomes. (For further discussion concerning the relationship between weight and self-reported compliance with diet, see the clinical parameter section below).

Although the findings in this study concerning perceived compliance with diet suggest that patients may have overestimated their compliance, the findings do show that the subjects do not perceive themselves as complying with their diet as well as they perceived themselves complying with taking medication or keeping follow-up appointments. This finding supports other research in which it was found that it is more difficult to comply with restrictions on behavior or changes in personal habits (i.e., changes in dietary habits) than to comply with taking medication (Davis, 1966). Although the overall compliance scores were high, the fact that the subjects in this sample did perceive themselves as complying with their considerably less than they perceived themselves complying with taking medication and keeping follow-up appointments, might suggest a relationship between actual and perceived compliance. That is, although the subjects may have overestimated their compliance behavior, they may overestimated each dimension (i.e., diet, medication, and follow-up appointments) to the same degree.

In summary, it was found that the subjects were positive concerning perceived family functioning. Moreover, the subjects perceived themselves as complying with their therapeutic regimen concerning diet, medications, and follow-up appointment more than "most of the time". However, when the three dimensions were examined

individually, differences were found in the subjects' perceptions. That is, subjects perceived themselves as (1) complying with their diet midway between "half of the time" and "most of the time", (2) complying with the medication regimen midway between "most of the time" and "all of the time", and (3) complying with follow-up appointments almost "all of the time".

The chart audit supported some, but not all of these patients' perceptions. That is, it appears that patients' perceived compliance with follow-up appointments consistent with actual compliance. In contrast, it appears that patients may have overestimated their compliance with taking medications and compliance with their diabetic diet. Nevertheless. although the patients did appear overestimate compliance, it appears they may have overestimated each dimension to the same degree thus showing a relationship between perceived compliance behavior and actual compliance behavior. In the next section clinical parameters, blood sugar levels and weights, will be discussed in relation to compliance behavior.

#### Clinical Parameters

Each subject had had a follow-up appointment for her/his diabetes within the month the questionnaire was completed. All clinical parameters, therefore, reflect patients' health status very close to the time they were interviewed. A comparison of the patients weight, height, and sex with the

Metropolitan Life Insurance height, weight chart showed that 92 percent of the subjects were overweight. Of the twenty-three patients who were overweight, four (18%) were less than twenty pounds overweight, eight (34%) were twenty to fifty pounds overweight, six (26%) were fifty to one hundred pounds overweight, and five (22%) were more than one hundred pounds overweight. Degree of obesity, however, was not significantly related to perceived family functioning (r = .16) or perceived compliance behavior (r = -.25).

This finding is not surprising characteristic of the adult onset diabetic is obesity. Moreover, the adult onset diabetic who has her/his weight under control usually does not need to be on an oral hypoglycemic or insulin to control her/his blood sugar. And, of course, one criterion for inclusion in the study was taking an oral hypoglycemic or insulin. Given the fact that 92 percent of the subjects in the sample were overweight, the subjects' perception of their compliance with diet seems an overestimation. This finding suggests that patients may have difficulty recognizing noncompliance concerning diet. Or, this finding may reflect the fact that patients answered questions in a way they thought the researcher expected.

Random blood sugar levels also were examined to explore a possible congruence between perceived compliance and actual behavior, the assumption being made that patients in control would more likely comply with treatment and have

a more positive perception of their compliance than patients This assumption was not supported by the not in control. findings. The blood sugar levels were not significantly related to perceived compliance behavior (r = -.01). Although the blood sugar levels of seven patients (28%) were within normal limits (70-120 mg/dl) and those of additional patients (8%) were within an acceptable range (60-150 mg/dl), sixteen (64%) of the patients were not control ( <60 or >150 mg/dl). A random blood sugar, of course, gives only a fragmentary glimpse of the patient's metabolic status (Bondy & Felig, 1971). Yet, this one time measure suggests that the majority (64%) of the subjects were out of control, even though they felt they were complying with a prescription whose intent was to help them achieve control.

This finding concerning the lack of relationship between blood sugar levels and perceived compliance behavior, may suggest several things. First, the findings may mean there is little or no relationship between compliance with taking medication and staying on the diabetic diet and the outcome measure, control of diabetes as measured by blood sugar levels. This is consistent with the findings of Williams and associates (1967) who found no association between compliance, as measured by direct observation and self-report, and control of diabetes. This would imply that appropriate outcome measures to indicate

diabetic control are difficult to identify (Malone 1976).

Second, the subjects in this sample may have overestimated their compliance with taking medication and following their diet. For example, Haynes and associates (1979) suggest self-reporting by patients usually results in findings of higher rates of compliance. This may be so because the patients may want to answer the questions in the way they think the researcher expects them to answer the questions. Or, the patients may be afraid to admit their noncompliance for fear their physician may become aware of their noncompliance.

Third, the findings regarding the chart audit may mean that indeed there is no relationship between perceived compliance behavior and actual compliance behavior. Further study is necessary to verify the relationship between perceived compliance and actual compliance behavior.

In viewing the blood sugar and weight of each patient, it was noted the random blood sugar was not directly related to the degree of obesity i.e., of the subjects whose ramdom blood sugar was within normal limits one was less than twenty pounds overweight, three were twenty to fifty pounds overweight, one was fifty to one hundred pounds overweight, and two were greater than one hundred pounds overweight. This finding is difficult to explain since there also was no relationship between the degree of obesity and the amount of diabetic medication the

patient was taking. For example, the patient who was less than 20 pounds overweight was taking 22 units of insulin while the two patients that were more than 100 pounds overweight were taking only oral hypoglycemics to aid in maintaining diabetic control.

Another finding that is worth noting concerns blood levels and perceived family functioning. The sugar correlation between perceived family functioning and blood sugar levels was r = -.32 approaching significance (p = <.058). Had the sample size been larger the correlation might have been higher and a significant relationship may have been found. The negative correlation implies that the higher the individual's blood sugar the lower individual's perceived family functioning score. The inverse relationship between these two variables might be explained by the fact that low perceived family functioning cause stress and/or overeating and stress and/or overeating causes the blood sugar to rise (Guthrie & Guthrie, 1977).

The finding of an inverse relationship between perceived family functioning and perceived compliance behavior is consistent with the findings of Williams and associates (1967), who, found in a study of insulin dependent diabetics, that the greater the degree of stress, the poorer the control of diabetes. Thus, there is a need for further research using a more uniform means of obtaining

blood sugar i.e., fasting blood sugar rather than random blood sugar. A significant relationship may have been found had fasting blood sugar levels been evaluated.

This tendency toward an inverse relationship between perceived family functioning and blood sugar levels has implications for nursing i.e., a need exists to assess perceived family functioning and to deal with the deficits. Solving perceived family functioning problems may result in improved diabetic control as indicated by the blood sugar levels.

In summary, those who perceived family functioning and/or compliance behavior as high were as likely to be overweight as those who perceived their family functioning compliance behavior to be somewhat lower. In addition, 92% of the subjects were overweight. Yet, they reported they complied with their diet midway between " half of the time" and "most of the time". Second, no significant relationship was found between random blood sugar and perceived compliance behavior. Moreover, 64 percent of the patients had random blood sugar levels that indicated their diabetes was not controlled. Third, there was no direct relationship between random blood sugar and degree of obesity. And finally, there was a tendency toward an relationship between random blood perceived family functioning. These findings suggest to the nurse the importance of assessing perceived

functioning and dealing with any deficits. Furthermore, the nurse should keep in mind that patients may tend to overestimate compliance with their diet.

In the next section, other variables that may influence perceived family functioning and percieved compliance behavior will be discussed.

#### Confounding Variables

The review of the literature indicated a host of variables that influence compliance behavior. For the purposes of this study, four were considered as confounding variables and their relationship to perceived compliance behavior explored. These four confounding variables included: (1) the number of years with diabetes; (2) the number of chronic illnesses other than diabetes; (3) the complexity of the regimen; and (4) hospitalization in the last six months.

Number of years with diabetes. Analysis of the data showed that the number of years the subject has had diabetes was not significantly related at the .05 level to perceived compliance behavior (r = .26). This finding supports the results of other studies that show that the length of time the patient had an illness is not associated with compliance behavior (Haynes et al., 1979). Yet, previous research also has shown that the continuation of therapy over time is negatively related to compliance behavior, i.e., the longer the patient is on a treatment regimen, the less he/she

complies (Haynes et al., 1979). Thus, the assumption was made in this study that the duration of the regimen was equal to the number of years the subject had diabetes. This assumption of equivalence was based on the fact that it is necessary for diabetic patients to comply with a diet from the time their diabetes is diagnosed. This means that since the diabetic diet is basic to all diabetic regimens, it is the first treatment prescribed to control diabetes.

The results showed, however, that this assumption The lack of a significant may not have been warranted. relationship between number of years with diabetes and perceived compliance behavior, then, may be due to several factors. First, the data concerning compliance behavior was Thus, patients elicited by self-report. may their compliance and the degree of overestimated overestimation may not be influenced by the number of the patient has had diabetes. Second, patient may not have accurately reported the number of years they had diabetes. That is, patients who have had diabetes for an extended period of time may have forgotten the actual number of years with diabetes and either underestimated or overestimated the length of time, thus resulting in the lack of relationship between the variables.

Analysis of the data also showed that the number of years the subject had diabetes was not related to percieved family functioning (r = -.16). Nevertheless, although the

results were not significant at the .05 level, the analysis showed an inverse relationship existed between the two variables. That is, those subjects who had diabetes the fewest number of years tended to perceive their family functioning more positively than those who had had the disease longer.

The reasons for this finding are difficult explain. For example, Rakel (1977) stated that illness of one family member affects all other family members and can affect the functioning of her/his family as well. Moreover, he stated that the more prolonged and complicated the illness, the greater its effect on the functioning of family. Since diabetes is a chronic and complex illness, it might be expected that the presence of a diabetic in a family would affect the functioning among its members. example, in diabetes the patient must eat certain foods in specific amounts, and at specified times throughout her/his Since the alteration in diet and eating habits must be permanent, there also may be a tendency to require the rest of the family to eat the type of food and at the times necessary for the diabetic patient. Thus, the family may be willing at the outset to cooperate with these changes, but as time goes on become less tolerant of the need for change.

There are several possible reasons for the lack of a significant relationship between perceived family

functioning and the number of years with diabetes. First, the diabetic patient is not generally debilitated and the not dependent on the rest of the family for their care. Thus, the length of time the patient has had diabetes, since diabetes in itself is not generally debilitating, may affect the functioning of the family. Second, the diet and possibly the cost of the regimen may be the only aspect of the regimen that affects the rest of the family. Thus, the family may have adapted to the cost and changes in diet habits and therefore its functioning was eating affected. Or, possibly, the rest of the family members were not required to make a change in their diets or eating habits and the increased cost may not have affected the family since most of the patients (64%) had adequate incomes (i.e., greater than \$20,000 per year). Third. participate in this study the subjects must have diabetes at least one year. Thus, the members of families may have perceived themselves as having adapted to the situation and the disease may no longer be impacting the family. Finally, the sample size was small. If the sample size was larger, a relationship may have been found. Each of these factors may have contributed to the lack of significant relationship found.

Number of chronic illnesses other than diabetes. It was found that the number of other chronic illnesses patients had was significantly related to perceived

compliance behavior (r = -.34, p < .05). The correlation between the variables, however, was low, indicating only a slight relationship. Moreover, it was found that relationship between number of chronic illnesses and perceived compliance behavior was inverse. That is, as number of chronic illnesses increased, the score of the perceived compliance behavior decreased. What this means is that patients with multiple diseases tended to percieve themselves as complying less than those who have fewer chronic illnesses. This is reasonable since as the number of chronic illnesses increases the complexity of the regimen For example, patient with additional increases also. chronic diseases usually have more medications prescribed to be taken at varied times throughout the day and have increased dietary restrictions.

No relationship was found, however, between the number of other chronic illnesses patients had and perceived family functioning (r = .25). This finding was surprising since illnesses of a complex and debilitating nature have a disruptive effect on family functioning (Rakel (1977) and an increasing number of chronic illnesses may tend to make illness, complex and, sometimes debilitating. It might have been expected then, that an increasing number of chronic illness would create problems within the family that were reflected in patients' perceptions of their family functioning.

There are several possible reasons why no significant relationship was found between the number of other chronic illnesses patients had and their perceptions of the functioning of their families. First, the other chronic illnesses they had may not have been debilitating. The most frequently mentioned other chronic disease was of hypertension. Sixty percent the subjects had hypertension. Hypertension in itself is not debilitating but may lead to other debilitating diseases such as cerebral vascular accident, kidney disease, and cardiac disease. Four subjects (16%) indicated they were taking medication for a heart problem but mentioned no other treatments restrictions. Peripheral vascular disease and arthritis can be debilitating and six subjects (24%) indicated having one of these diseases. However, no subjects expressed being incapacitated. An additional possibility for no significant relationship between the number of other chronic illnesses and perceived family functioning is that the family may be functioning to help or the family may have adjusted to the chronic illnesses.

Complexity of the regimen. Analysis of the data also revealed that the number of medications the subjects were taking was not significantly related to perceived compliance behavior (r = -.11). This finding was at variance with previous research findings. For example, Haynes and his colleagues (1979), in a review of the

literature, found consistent evidence which suggested that multiple drugs reduced compliance behavior. In six of the eleven studies they reviewed, compliance fell off sharply when the number of medications reached three or more. In this study, however, only seven subjects (28%) were taking three or more medications. The reason for the lack of a significant relationship between number of medications the patient was taking and compliance, then, may be due to the fact that compliance behavior was elicited by self-report and the subjects were answering to the best of their knowledge. That is, they perceived themselves to be complying with their physicians' prescriptions when indeed they may not have been following their recommendations.

The results also showed no statistically significant relationship between the number of times per day the subjects were taking medication and perceived compliance behavior (r = .12). This finding is not surprising given the fact that past research also has produced no clear consensus linking frequent dosage with low compliance (Haynes et al., 1979). It appears, than, that the number of times per day a patient takes medication does not influence compliance behavior as perceived by the patient.

In a similar vein, no statistically significant relationship was found between perceived compliance behavior and the number of other dietary restriction (r = .16). Again, this finding may be due to the fact that compliance

was measured by subjective self-reports and the subjects may not have been following all the dietary restrictions as well as they indicated they were complying. Or, possibly, when patients are already on a complex diet, such as a diabetic diet, they may not perceive added diet restrictions as increasing the complexity of the regimen.

Furthermore, the complexity of the regimen is increased by other recommendations that are prescribed in addition to the recommendations necessary for the diabetic regimen. Studies have revealed that compliance was lower for patients for whom both drugs and other recommendations were made (Haynes et al., 1979). In this study, the majority (22) had no other treatments prescribed. Three subjects mentioned exercise as another treatment. There were too few other treatments indicated by the subjects to be of any statistical significance.

In summary, none of the measures of complexity of regimen showed a relationship to compliance behavior. Perhaps if the complexity of the regimen was viewed totally, a significant relationship may have been found. Or, perhaps, when a patient already has a complex regimen, which is common to diabetes, the addition of further dietary restrictions and medication, may not be reflected in the patient's perception, i.e., he/she may not perceive herself/himself as complying to any lesser degree.

Hospitalized in the last six months for diabetes. Hospitalization in the last six months for diabetes may involve reinforcement teaching concerning diabetes. Accordingly, it was postulated that such reinforcement teaching might act as a cue for compliance and temporarily improve compliance behavior. This relationship, however, could not be explored since only one subject had been hospitalized in the six months prior to the study.

### Nursing Implications for Practice

Advances in medicine, have increased life expectancy. One outcome of this increased life expectancy is chronic illness. Individuals with such chronic diseases, however, can reach a maximum potential for daily living. But compliance with a therapeutic regimen is necessary if they are to function at their optimum level. And, the need for such compliance has important implications for nursing practice.

A primary responsibility of the nurse is to assist patients to reach their maximum potential for daily living. Accordingly, the nurse must recognize those factors that individuals perceive as motivating or as hindering the achievement of this goal. One factor that individuals may perceive as motivating or hindering to compliance behavior is the functioning of their family. This is so because the family is the core of a person's environment. According to King (1971), man and his environment is the central focus

for the framework of nursing.

Given this focus, King's (1971) theory of nursing seems particularly relevant for this study. King states that man functions in a social system which includes the Moreover, she states that man functions family unit. through interpersonal relationships which could refer to family functioning. Further, King states man functions in terms of her/his perception, i.e., in terms of conscious awareness. All of King's concepts (social system, interpersonal relationship, and perceptions) influence the other words. concepts of life and health. In an individual's conscious awareness of functioning within the family through interactions with family members influences her/his life and health. Thus, since according to King, an individual's perception of the functioning within the family influences her/his life and health, and since compliance behavior in chronic illness also influences life and health, it seemed reasonable to expect there may be a relationship between perceived family functioning and stated compliance behavior.

This study was an effort to assess the relationship between the perceived family functioning and perceived compliance behavior of adult onset diabetics. This effort was not successful. That is, no relationship was found between perceived family functioning and perceived compliance behavior yet, as suggested above, the negative

findings of this study do not necessarily negate the fact that the family and the behavior of its members to one another influence compliance behavior. For example, it was found in this study that an inverse relationship, albeit low, existed between perceived family functioning and the random blood sugar, i.e., as the random blood sugar elevated the perceived family functioning score declined. This finding suggests that the nurse has an important role to play in fostering the family functioning and compliance of patients with diabetes.

For example, the professional role of nursing in ambulatory care settings involves the systematic assessment of patients' health states as well as systematic assessment and management of compliance behavior. Traditionally, nurses have been instrumental in making the prescribed regimen understandable and possibly even helping the patient feel competent to manage the regimen. However, transmitting information alone is not enough to overcome noncompliance. It is also necessary to acknowledge that the therapeutic regimen is only a part of the life regimen the patient must manage. Thus, one aspect of the nurse's role is to promote patient participation in identifying barriers to compliance and helping the individual resolve difficulties that are interfering with compliance.

To perform this aspect of her/his role the nurse must first systematically assess the patient's problem.

He/she must ascertain whether or not the patient has achieved the goal of treatment (in the case of diabetes, control of blood sugar levels). By reviewing the patient's record for blood sugar levels, weight, urine glucose levels, and alpha hemoglobin (if one is available), as well as asking the patient questions regarding her/his health state, the nurse can ascertain which patients have not reached their treatment goals. Next, she must determine whether or not the regimen prescribed is vigorous enough to achieve the treatment goal and if the patient has adequate information concerning the therapeutic regimen. If the answer to these are affirmative and the patient has not reached her/his treatment goal, then the nurse may consider compliance to be a problem.

Although the results of this study suggest that patients tend to overestimate compliance, most particularly compliance with diet, Haynes and his associates (1979)indicate that the most useful approach to elicit noncompliance among patients in the clinical setting simply to ask the patients in a nonthreatening fashion, whether they are or are not compliant. It is likely that the patients who will admit to low compliance will be the ones who will show the greatest response to compliance improving strategies. In other words, those patients who do not perceive themselves as noncompliant will not see a need questionnaire to change their compliance behavior. A

similar to the one used in this study may be used to assess systematically the patients' subjective view of compliance behavior. If it is ascertained that compliance with the therapeutic regimen is a problem, it is appropriate to investigate variables that may be interfering with compliance.

Based on findings from this study, as well research, variables that the nurse should investigate that may be interfering with compliance are: (1) number of years with diabetes; (2) complexity of the regimen; (3) number of chronic illnesses other than diabetes; and (4) the separate components of perceived family functioning as well as the total perceived family functioning. For example, although this study did not find significant relationships between compliance behavior and the complexity of the regimen, and the number of years with diabetes, previous research has shown a relationship between these variables. Until further research has been conducted to substantiate this lack of evidence of a relationship between compliance behavior and complexity of the regimen and the number of years with diabetes, it would be wise for the nurse to continue to investigate if these variables may be interfering with compliance behavior because the size of the sample for this study was small and representative of all diabetic patients and, since previous studies found a relationship, these variables may in fact

influence compliance behavior.

Moreover, the significant inverse relationship found between the number of other illnesses and perceived behavior indicates that compliance as diabetes is of complicated by an increased number other chronic illnesses, perceived compliance behavior decreases. The nurse, then, should give particular attention the assessment of patients who have multiple chronic illnesses in addition to their diabetes to ascertain if such patients are having difficulty with compliance behavior. patients may need added assistance in planning and implementing strategies to improve compliance behavior.

In addition, although no significant relationship was found between total perceived family functioning and perceived compliance behavior in this study, there is strong reason to believe that the behavior of family members toward the patient affects her/his compliance behavior (Baekeland and Lundwell, 1973; Heinzelmann and Bagley, 1970; Litman, 1966; Oakes et al., 1970; West et al., 1977). the separate components of family functioning (adaptation, partnership, growth, affection, resolve) may have influence on the degree to which a patient follows one or more aspects of the treatment prescribed (e.g., medication, follow-up appointments). Therefore, is appropriate to investigate if any of the components family functioning may interfere with compliance behavior to

ascertain if nursing intervention concerning the patient's family functioning is warranted.

And finally, the finding of an inverse relationship between perceived family functioning and random blood sugar (i.e., declines in perceived family functioning score with elevation in random blood sugars) suggests the need for systematic assessment of perceived family functioning. This is so because how the patient interacts with her/his family may have an influence on the outcome, diabetic control.

It would appear that a tool similar to Smilkstein's Family APGAR screening tool might be useful for such a systematic assessment. The Family APGAR was developed for use, is easily administered in the clinical clinical setting, and has been shown to have construct validity (Good et al., 1979). The instrument can be used to identify areas in which deficits in family functioning exist (i.e., adaptation, partnership, growth, affection, or resolve). By means of a questionnaire the patient and the nurse can together identify problem areas in family functioning. Further discussion of the problem areas can be initiated by using open- ended questions suggested by Smilkstein (Table 2, Appendix I). Open-ended questions may help to more specifically identify the problems.

Once the nurse and the patient determine the way in which the functioning of the family adversely affects her/his ability to follow the treatment regimen, it is

appropriate to implement the next step in the nursing process. That is, the nurse, together with the patient, plan strategies to overcome some of the family functioning problems and compliance behavior problems as well. Such strategies may require the involvement of the whole family or only of certain members. One strategy may be to provide guidance and counseling to family members. If the family problems are very complex, another strategy may be to refer the family to a mental health clinic for family therapy. Still another strategy may be to educate the family as well as the patient concerning diabetes, including a discussion of the effect that diabetes may have on the family. example, the alteration of diet and eating habits such as eating at specified times may require the cooperation of the whole family. In addition, it may be helpful to discuss with the family the effect that the family may have on the compliance behavior of the individual with diabetes as well as the effect of perceived family functioning on the random blood sugar. Such educating of the patient and the family may be achieved by the nurse educating the individuals herself/himself or it may be achieved by referring the patient and the family to diabetic education programs.

Following the planning of strategies, the third step of the nursing process involves implemention of the strategies by the patient and the family, that were planned by the nurse and the patient, to improve the patient's

family functioning and compliance behavior. The nurse can offer support to the patient and family as they implement the strategies.

After implementation of the strategies, the final step of the nursing process is to evaluate. The nurse can evaluate whether the patient's perception of the functioning of her/his family has improved. This evaluation can be achieved through an interview. It is more important that the individual perceives her/his family functioning to have improved rather than the nurse perceiving the individual's family functioning to have improved. This is so because according to King (1979) the patients perceptions are her/his image of reality. And, the patients image of reality will do more to influence the patient behavior than the influence of the nurses image of reality on the patients behavior.

The nurse should then evaluate if the improved perception of family functioning and the improved stated compliance behavior has had an effect on the outcome. The patient and the nurse can subjectively evaluate if there was an improvement in how the patient appears and her/his general feeling of well being. The records can be evaluated to ascertain if there was an increase in weight lose if the patient was overweight. Also, the nurse can ascertain if the improved perceived family functioning resulted in improved diabetic control as indicated by random blood

sugar. By these means the nurse and patient could evaluate if there has been an improvement in the patient's health state and if the individual has reached her/his maximum potential for daily living.

In summary, the purpose of this study was to analyze the relationship between perceived family functioning and perceived compliance behavior. Although this study did not produce evidence to support a relationship between perceived family functioning and perceived compliance behavior, until further research substantiates this finding, the nurse should realize that chronically ill patients usually live within a family and the family may influence compliance behavior as well as the health state. Thus, when assessing a patient with chronic illness, the nurse should assess the individual's family functioning and her/his compliance behavior in addition to the patients health state. If a problem is identified, the nurse should continue with the in an effort to subsequent steps of the nursing process alleviate the problem.

### Implication for Nursing Education

The results of this study have several implications for nursing education. Although the curriculum of nursing schools usually include family content, there is a need to further extend education in the area of family in the management of chronic illness including diabetes. The tendency toward a slight inverse relationship (r = .-32 p = < .058)

between perceived family functioning and random blood sugar suggests the importance of the role of the family of That is, it appears that as the patients with diabetes. perceived family functioning declines the blood sugar of the diabetic increases. This would suggest the importance family interaction on diabetic control. King (1971) implied that nursing should be concerned with the patient as well as the environment in which the individual functions. environment includes the patient's family and/or social system. King's theory should be included at all levels of nursing education, undergraduate as well as graduate. A course on the family and other social systems that influence the life and health of patients should be included in the nursing curricula.

The concept of family functioning should be taught as well as a means to assess family functioning. Introduction of a family functioning assessment tool such as Smilkstein's Family APGAR may be useful to professional nursing students. Nursing students should be taught the importance of teaching and working with families of patients with chronic illness as well as the patients themselves.

The teaching of the concept of family functioning should not be limited to only present students of nursing but should be extended to professional nurses in practice through continuing education classes as well as through staff development classes at various health care facilities.

A family functioning assessment tool should be introduced to professional nurses in practice as well. Practicing professional nurses should also be made aware of the importance of teaching and working with the families of patients with chronic illness.

Nursing students and nurses in practice should also be taught the importance of assessing compliance behavior, i.e., compliance behavior being conducive to achievement of control in diabetes. They should be made aware that compliance behavior elicited by self-report, may be overestimated and, therefore, they should seek means whereby compliance behavior can more effectively be assessed, i.e., several assessments of alpha hemoglobin.

### Implication for Future Research

As nurses, we need to recognize our lack of understanding of compliance behavior of patients with chronic illness. This lack of understanding is especially prevalent in the area concerning the influence of family functioning on compliance behavior. Continuing research is needed to overcome this lack of understanding. This study has investigated the relationship between perceived family functioning and percieved compliance behavior of patients with the chronic illness, diabetes. No relationship was found between the two variables. One study was located that investigated the relationship between family functioning, as determined by a family therapist, and compliance behavior

(Steidl et al., 1980). Like this study, no relationship was found between total family functioning and compliance behavior. However, in Steidl and associates' study (1980) a relationship was found between some of the components of family functioning and compliance behavior. More descriptive studies concerning family functioning compliance behavior as well as some experimental studies should be completed to explore further the possibility that there is no relationship between total perceived family functioning and adherence to a regimen by patients who are chronically ill. In addition, further investigation of the individual components of family functioning and their relationship to compliance behavior, in other illnesses as well as with diabetes, may prove beneficial.

The confounding variables (number of years with diabetes, complexity of regimen, and hospitalization in the last six months) were not statistically significant with perceived compliance behavior in this study. But, the number in this sample was small and compliance behavior was assessed by self- report. A larger sample or a more objective means of measuring compliance behavior of the diabetic may have produced, significant relationships between these variables. By contrast, sample size and methodology did not appear to have an effect on the influence of other chronic diseases on perceived compliance behavior. That is, a statistically significant negative

correlation between perceived compliance behavior and the number of other chronic illnesses in addition to diabetes was found. All of these findings need to be reevaluated in future research to substantiate the findings.

It is difficult to find a totally objective means of measuring compliance behavior of the diabetic that from a one time measurement can give sufficient evidence to draw a conclusion concerning the compliance behavior of individual. A longitudinal study would be necessary for objective measures of compliance behavior in the diabetic to be of value. However, the one time indirect measure of weight as related to compliance behavior suggests that patients do not recognize noncompliance with diet, i.e., percent of the subjects were overweight. Yet, the subjects, on the average perceived themselves as complying with their diets midway between "half of the time" and "most of the time". More studies should be completed to investigate the relationship between percieved compliance behavior and compliance behavior to test the actual veracity of self-report.

As stated previously, conducting a study similar to this study might provide further substantiation of its findings. Further refinement of the instrument as well as increasing the number of questions for each component may be beneficial. By increasing the number of questions for each component, the individual components of perceived family

functioning could be evaluated adequately. Measuring compliance behavior by more objective means rather than self-report may give a more accurate estimate and more convincing evidence of compliance behavior. However, than a one time measurement of objective parameters are usually necessary to evaluate compliance behavior in the In addition, using more stringent clinical control may add veracity to the findings. Replicating a study similar to this study but altering certain variables may add credibility to the findings of this study. Using a larger sample size would give a truer picture of the population than a smaller sample size because the larger the sample the smaller the chance of error. Replicating the study in other settings, in different geographical areas, and with patients with other chronic illnesses such hypertension, cardiovascular disease, and arthritis may either substantiate the findings of this study or show a between perceived family functioning relationship perceived compliance behavior.

If further investigations find a correlation between certain components of family functioning and compliance behavior, further study should be done to ascertain the direction of the relationship. For example, do the components of family functioning influence compliance behavior or does compliance behavior influence the components of family functioning? Possibly they influence

each other in a circular fashion. Further studies could also test the predictive value of family functioning and evaluate whether nursing interventions with families that have areas of dysfunction can promote adherence to the therapeutic regimen.

need for There continues to be a systematic assessment of the family. A few family assessments tools Pless and Satterwhite (1973)have been developed. developed the Family Functioning Index which was shown to be valid and reliable for family's of children with chronic illness. Smilkstein's (1978) Family APGAR is still in the process of being tested. As of now Smilkstein's and Pless and Satterwhite's tools need further testing to substantiate their value for systematically assessing family functioning in other types of family situations. Developing valid and reliable means to assess family functioning are important to practice, education, and research.

Nurses in the clinical setting can contribute to research. As the nurse treats the patients holistically, including assessing the family unit and its effect on the patient's health state, the nurse should document the outcome in the patient's record concerning family functioning and its influence on compliance behavior. Publishing descriptive reports of their findings would be a benefical contribution to the knowledge base of nursing.

In summary, suggestions for future research include:

(1) investigating the individual components of family functioning and their relationship to other chronic illnesses as well as to diabetes: (2) conducting longitudinal study using objective means of measuring compliance behavior rather than self-report and more stringent clinical control; (3) investigating the relationship between self-reported compliance behavior actual compliance behavior; (4) using a larger sample size, in other settings, and in other geographical areas; conducting experimental intervention studies to investigate the predictive value of family functioning for compliance behavior and blood sugar levels; and (6) continuing study the effect of confounding variables on perceived family functioning and perceived or actual compliance behavior in chronic illness.

### Summary

Chapter VI provided a summary and interretation of the research findings in relation to the hypothesis and confounding variables. Nursing implications for practice, education, and research were discussed.

# APPENDIX A

CONFIDENTIAL PATIENT

DATA SHEET

(1-2)	Patient	No.		
(3-5)	Date	/	_	

## MICHIGAN STATE UNIVERSITY SCHOOL OF NURSING Master's Thesis

# Confidential Patient Data Sheet

Setting		<del></del>		
Please complete. feel free to ask for a	_	e any questions	concerning	this
Age				
Sex: Male	Female2			
Race: Blackl	White2	Other3		
Income: Less than	\$10,000/ye	ar \$10,000	-19,999/yea	2
\$20,000 c	or greater/y	ear		
Marital status:	Singlel	Married2	Separated_	3
	Divorced4	Widow		
Please indicate twith whom you live		ship, sex, and	age of the p	people
Sex	Age	Relationship		
1.				
2.				
3.				
4.				

Sex	· Age	Relationship (cont'd)
5.		
6.		
7.		
Number of year	ars you have h	ad diabetes.
1-5 6-10	) 11-15	3 16-20 more than 20 5
Medications y	you are taking	for your diabetes.
Insulin	Pill2	
Number of year	ars you have b	een following the present course
of treatment	for your diab	etes
What other ildiabetes?	llnesses are y	ou being <u>treated</u> for other than
No other	r illnessesl	Asthma or Emphysema2
High Blo	ood Pressure	Arthritis4
Poor ci	culation in 1	egs Thyroid Problems6
Heart P	roblems7	Female Problems8
Indicate	any other il	lnesses
		9
What other didiabetic dies		ns are you on other than your
None1	Low Salt	Low Cholesterol3
Indicate	any other	

What other medications are you taking other than your insulin or oral hypoglycemics?	
How many times each day do you take medication?	
Besides your diet and medications what other treatments of you follow?	of
Have you been hospitalized for your diabetes in the last months?	six
YesNo	

# APPENDIX B

QUESTIONNAIRE

FAMILY FUNCTIONING SECTION

### Patient Questionnaire

Below is a series of statements that describe patient's attitudes concerning their families. Patients vary in the way they view their family. I am interested in how you view your family.

Directions: Read each statement carefully and then circle the most appropriate category that represents how you feel about each statement made concerning your family. Please circle only one answer per question. Do not skip any questions.

There are no right or wrong answers to these questions.

1. I receive help from my family when something is troubling me.

Strongly
Agree Agree Undecided Disagree Disagree

2. My family spends time together for family activities.

Strongly Agree Undecided Disagree Disagree

3. In my family we are not encouraged to express our opinions.

Strongly Agree Undecided Disagree Disagree

4. Our family encourages each member to be independent.

Strongly Agree Undecided Disagree Disagree

5. Our family does not work well together toward a common goal.

Strongly Agree Undecided Disagree Disagree

My family accepts my wishes to take on new activities. 6. Strongly Strongly Undecided Disagree Disagree Agree Agree We encourage family members to take care of their own 7. problems. Strongly Strongly Agree Undecided Agree Disagree Disagree Our family does not have areas of common interest. 8. Strongly Strongly Agree Undecided Disagree Disagree Agree My family gets upset when I spend time away from home. 9. Strongly Strongly Undecided Disagree Disagree Agree Agree In my family we have difficulty expressing affection 10. to each other. Strongly Strongly Agree Agree Undecided Disagree Disagree 11. I feel love for my family members. Strongly Strongly Undecided Disagree Agree Agree Disagree 12. My household chores do not get done if I am unable to do them. Strongly Strongly Agree Undecided Disagree Disagree Agree 13. Expression of anger is not easy for my family to accept. Strongly Strongly Undecided Disagree Disagree Agree Agree

14. My family discusses problems such as allowances, clothing, and household responsibilities.

Strongly Agree Undecided Disagree Disagree

15. Our family does not enjoy being together.

Strongly Strongly Agree Undecided Disagree Disagree

16. Our family would not ask for help from community agencies.

Strongly Strongly Agree Undecided Disagree Disagree

17. My family responds to my feelings of love.

Strongly
Agree Agree Undecided Disagree Disagree

18. The amount of family's money I am allowed for personal needs is fair.

Strongly Strongly Agree Undecided Disagree Disagree

19. It is not easy for my family to deal with change within the family unit.

Strongly Strongly Agree Agree Undecided Disagree Disagree

20. I accept it when other members of the family spend time doing things differently from the things I do.

Strongly Agree Agree Undecided Disagree Disagree

21. The amount of responsibility I have in our family is fair.

Strongly Agree Undecided Disagree Disagree

22. Our family is willing to accept help or assistance from friends.

Strongly Agree Undecided Disagree Disagree

23. Responsibility is not divided fairly among our family members.

Strongly Agree Undecided Disagree Disagree

24. Change within the family is not easy for me to deal with.

Strongly Agree Undecided Disagree Disagree

25. I feel my family cares what happens to me.

Strongly Strongly Agree Undecided Disagree Disagree

26. The amount of space provided for may personal belongs is fair.

Strongly Strongly Agree Undecided Disagree Disagree

# APPENDIX C

QUESTIONNAIRE

COMPLIANCE SECTION

Below is a series of statements that describe certain things that patients do concerning diet, medication, and keeping of health care appointments. Patients vary as to the way that diabetes affects their lives. I am interested in how you respond to what the doctor, nurse, or dietician has told you to do because of your diabetes.

Directions: Read each statement carefully and then circle the <u>most appropriate category</u> that represents the extent to which you have done what the statement indicates during the past <u>two weeks</u>. Please circle only <u>one</u> answer per question. Do not skip any questions.

1. I have eaten snacks that are not on my diet.

Never Seldom Half of Most of All the the time the time

2. I have been known to forget to take my medication.

Never Seldom Half of Most of All the the time time

3. I have eaten more than the number of calories ordered by the doctor.

Never Seldom Half of Most of All the the time the time

4. I have tried to at least maintain my present weight.

Never Seldom Half of Most of All the the time the time

5. I have taken my medicine in the amounts ordered.

Never Seldom Half of Most of All the the time the time

6. I have eaten the foods I was told to avoid.

Never Seldom Half of Most of All the the time the time

7. I have not ignored my diet when I have eaten away from home. Seldom Half of Most of All the Never the time the time time 8. I have taken my medicine only when I have felt like I needed it. Seldom Half of Most of All the Never the time the time time 9. I have eaten only the amounts of food suggested on the diet ordered by the doctor. Seldom Half of Most of All the Never the time the time time 10. I have gotten mixed up and have taken my medicine wrong. Never Seldom Half of Most of All the the time the time time I have forgotten to take my medicine when I have 11. been away from home. All the Half of Most of Never Seldom the time the time time I have followed my diet as ordered by the doctor. 12. All the Never Seldom Half of Most of the time the time time I have watched for the negative (bad) effects of my 13. medicine. Seldom Half of Most of All the Never

the time the time time

the time

I have gotten my prescriptions refilled before or as

Half of

the time

Most of

time

All the

soon as I have run out.

Never

Seldom

14.

15. Following my diet has interferred with my normal daily activities.

Never Seldom Half of Most of All the the time the time

16. I have taken my medicine at the times ordered by my doctor.

Never Seldom Half of Most of All the the time the time

Directions: Read each statement carefully and then circle the <u>most appropriate category</u> that represents the extent to which you have done what the statement indicates during the past <u>six months</u>. Please circle only <u>one</u> answer per question. Do not skip any questions.

17. I have been known to forget my appointments.

Never Seldom Half of Most of All the the time the time

18. I have had my blood sugar checked whenever the doctor suggested I should.

Never Seldom Half of Most of All the the time the time

19. I have not gone for my follow-up appointments when I have felt good.

Never Seldom Half of Most of All the the time the time

20. I have reported reactions from my diabetic medication to the doctor.

Never Seldom Half of Most of All the the time time

21. I have kept my appointments to see the doctor or nurse.

Never Seldom Half of Most of All the the time the time

22. I have avoided having my blood sugar drawn whenever possible.

Never Seldom Half of Most of All the the time the time

23. I have gone to the doctor only when I have felt bad.

Never Seldom Half of Most of All the the time the time

24. If something has occurred making it impossible for me to keep my appointment I have rescheduled my appointment for as soon as possible.

Never Seldom Half of Most of All the the time the time

### APPENDIX D

CHART AUDIT WORK SHEET

# CHART AUDIT WORK SHEET

Patient No	
Most recent physical measurements: Height Weight	•
Age at onset of diabetes:	
Number of years with diagnosed diabetes:	
Type of calculated diabetic diet:	
Follow-up appointments for diabetes scheduled in the last six months. (Circle if did not keep appointment).	
Date:	
Weight each visit:	
Blood Sugar results each visit:	
Type of test:	
Normal lab value:	_
Patient lab value:	_
Urine glucose each visit:	
Type of test:	_
Glucose:	
Ketones:	_

# APPENDIX E

LETTER TO PHYSICIAN

10751 Barnes Rd. Durand, Mi. 48429 March 17, 1981

Dear Dr.

I am Barbara Sipes R.N., a M.S.U. graduate student, conducting research for my Master's in nursing thesis. I would like your permission to use some diabetic patients from your private practice. A brief outline of my plans are as follows.

I plan to begin my, study "The Relationship Between Family Functioning and Compliance Behavior of the Adult Onset Diabetic," in March. I will collect data until 25 subjects have been included in the study. It is necessary that either you or your nurse ask your diabetic patients if they would consider participating in a research project and give them the introductory letter explaining the nature of the study. If an individual agrees to participate he/she must sign the consent form. The consent form will also allow me access to the following information from the patient's record concerning the specified criteria necessary to be part of this study.

- A known diabetic as indicated in the records for at least one year prior to the time of selection
- Onset after age 29
- Between 31-70 years of age
- On a calculated diabetic diet
- On an oral hypoglycemic or less than 60 units insulin per single dose
- Seen at least two times per year in an ambulatory care setting

In addition to the above mentioned specified criteria the subject must live with at least one other person, must not be pregnant, and must be able to fill out the questionnaire without assistance. I will contact each subject who meets the specified criteria by phone and will arrange a time with the individual when I can administer the questionnaire.

I will need a member of your staff to identify prospective subjects when they come in for appointments, give the subjects the introductory letter and consent form, and refer them to me. It should involve 5-10 minutes of their time. I will be the only person involved in the data collection besides the staff member who identifies the diabetic patients. I will need additional information from the chart concerning blood sugar, urine glucose, weight, and number of follow-up appointments in the last six months.

Patients' rights, confidentiality, and anonymity will be safeguarded as follows:

- Patients will not be solicited by the researcher
- Patients will be assured as to their right to refuse or withdraw without it affecting their care in any way
- As much privacy will be provided as possible give the physical restraints of the situation
- The researcher will administer the questionnaire
- The questionnaire will be coded with no name on the questionnaire
- The consent form will be separated from the questionnaire
- No one from the ambulatory care setting will be permitted to read the questionnaire following completion
- Data will be accessible only to the researcher and thesis committee

If this is agreeable please sign the attached consent form.

Sincerely,

Barbara Sipes R.N.

I grant permission for Barbara Sipes R.N. access to clients from my private practice to conduct research for her Masters'in Nursing thesis concerning "The relationship between family functioning and compliance behavior of the adult onset diabetic".

Signature		 <del></del>
Date	 	

# APPENDIX F

CHECK LIST OF PATIENTS

ADMITTED TO THE STUDY

Date:
-------

# CHECK LIST OF PATIENTS ADMITTED TO THE STUDY

Obtain from patient record:
A known diabetic as indicated in the records for at least one year prior to the time of selection
Onset of diabetes after age 29
<pre>Age at time of admission to the study -no more than 70 no less than 31</pre>
On a calculated diabetic diet
On an oral hypoglycemic or less than 60 units insulin per single dose
Seen at least two times per year in an ambulatory care setting
atient reports:
Lives with at least one other person
Is able to read and fill our the questionnaire without assistance
Is not pregnant

# APPENDIX G

INTRODUCTORY LETTER

# MICHIGAN STATE UNIVERSITY SCHOOL OF NURSING

Barbara Sipes R.N., a Michigan state graduate nursing student, is conducting a study for her thesis which is a part of the requirements for a master's degree in nursing. She is looking for diabetic patients who live with at least one other person to participate in her study. The study is seeking to determine the relationship between family functioning and its influence on the adult diabetic following the treatment plan.

The study will involve completing one questionnaire with two parts, one concerning your family and one concerning following your diabetic treatment plan. The questionnaire should take about 20-30 minutes to complete. If you are willing to participate, the following consent form will need to be signed. The consent form will indicate you agree to participate and it will also grant her permission to obtain the following information from your medical records:

- A known diabetic for a least one year prior to the time of selection
- Onset after age 29
- Between 31-70 years of age
- On a calculated diabetic diet
- On an oral hypoglycemic or less than 60 units insulin per single dose
- Information concerning weight, blood sugar, urine glucose, and appointments

If your records indicate you meet this criteria she will contact you by telephone to arrange a time when you could fill out the questionnaire. She will arrange to meet you at your physician's office or bring the questionnaire to your home, whichever you prefer.

Thank you so much for your time and cooperation.

APPENDIX H

CONSENT FORM

#### MICHIGAN STATE UNIVERSITY SCHOOL OF NURSING CONSENT FORM

Investigator: Barbara Sipes, R.N., B.S.N.

Graduate Student, Family Nurse Clinician

School of Nursing

Michigan State University

(313) 266-4490

The study in which you are about to participate is seeking to determine the relationship between family functioning and its influence on adult diabetic following the treatment plan. This study is being conducted by myself as part of the requirements for a master's degree in nursing. The study may not benefit you personally, but we hope the results of this study will help us improve health care delivery for all diabetic patients.

This study will involve completing one questionnaire two parts, one concerning your family and concerning following your diabetic treatment plan. questionnaire should take about 20-30 minutes to complete and will require you to respond to the questions as honestly and accurately as possible. Additional information such as age, sex, race, income, relationship of family members, as well as specific questions about your diabetes and other illnesses will also be obtained. It will be necessary to obtain information from your medical record. Your answers will be kept in complete anonymity and no attempt will be made to identify you in any manner. You are free to withdraw at any time. Withdrawal from the study will in no way affect the care you are now receiving.

As a result of participation in this study you may become more aware of your disease and/or your family relationships. If this occurs, I am willing to speak with you or refer you to a counselor (at your expense) for further assistance. If you have any questions, feel free to ask me immediately or call me. Thank you for your time and cooperation.

Barbara Sipes
Family Nurse Clinician Graduate Student
Telephone: (313) 266-4490

I voluntarily consent to partial have had an opportunity to a from the study at any time with	sk questions. I may withdraw
Signature of Subject	Date
Signature of Investigator	 Date

# APPENDIX I

FAMILY APGAR TABLES

#### FAMILY APGAR TABLES\*

TABLE 1. Definitions of Family APGAR Components

Component	Definition
<u>A</u> daptation	Adaptation is the utilization of intra and extrafamilial resources for problem solving when family equilibrium is stressed during a crisis.
<u>P</u> artnership	Partnership is the sharing of decision making and nurturing responsibilities by family members.
<u>G</u> rowth	Growth is the physical and emotional maturation and self-fulfillment that is achieved by family members through mutual support and guidance.
<u>A</u> ffection	Affection is the caring or loving relation- ship that exists among family members.
Resolve	Resolve is the commitment to devote time to other members of the family for physical and emotional nurturing. It also usually involves a decision to share wealth and space.

<sup>\*</sup>Smilkstein, Gabriel. The Family APGAR: A Proposal for a Family Function Test and Its Use by Physicians, <u>The Journal</u> of Family Practice, Vol. 6, No. 6, 1978.

TABLE 2. Open-ended Requests for Family Function Information

Component	Relavant Open-Ended Questions
Adaptation	How have family members aided each other in time of need? In what way have family members received help or assistance from friends and community agencies?
<u>P</u> artnership	How do family members communicate with each other about such matters as vacations, finances, medical care, large purchases, and personal problems?
Growth	How have family members changed during the past years? How has this change been accepted by family members? In what ways have family members aided each other in growing or developing indepenent life-styles? How have family members reacted to your desires for change?
Affection .	How have family members responded to emotional expressions such as affection, love, sorrow, or anger?
Resolve	How do members of your family share time, space and money?

TABLE 3. Family APGAR Questionnaire

	Almost always	Some of the time	Hardly ever
I am satisfied with the help that I receive from my family* when some-thing is troubling me.			
I am satisfied with the way my family* discusses items of common interest and shares problem solving with me.			
I find that my family* accepts my wishes to take on new activities or make changes in my life-style.			
I am satisfied with the way my family* expresses affection and responds to my feelings such as anger, sorrow, and love.			-
I am satisfied with the amount of time my family* and I spend together.			

Scoring: The patient checks one of three choices which are scored as follows: 'Almost always' (2points), 'Some of the time' (1 point), or 'Hardly ever' (0). The scores for each of the five questions are then totaled. A score of 7 to 10 suggests a highly functional family. A score of 4 to 6 suggests a moderately dysfunctional family. A score of 0 to 3 suggests a severely dysfunctional family.

<sup>\*</sup>According to which member of the family is being interviewed the physician may substitute the word 'family' for either spouse, significant other, parents, or children.

TABLE 4. What is Measured by the Family APGAR?

Component	
<u>A</u> daptation	How resources are shared, or the degree to which a member is satisfied with the assistance received when family resources are needed.
<u>P</u> artnership	How decisions are shared, or the member's satisfaction with mutuality in family communication and problem solving.
<u>G</u> rowth	How nurturing is shared, or the member's satisfaction with the freedom available within the family to change roles and attain physical and emotional growth or maturation.
<u>A</u> ffection	How emotional experiences are shared, or the member's satisfaction with the intimacy and emotional interaction that exists in a family.
Resolve	How time (and space and money*) is shared, or the member's satisfaction with the time commitment that has been made to the family by its members.

<sup>\*</sup>Besides sharing time, family members usually have a commitment to share space and money. Because of its primacy, time was the only item included in the Family APGAR; however, the physician who is concerned with family function will enlarge her/his understanding of the family's resolve if he/she inquires about family member's satisfaction with shared space and money.

### APPENDIX J

QUESTIONS USED FOR

DATA ANALYSIS

#### QUESTIONS USED FOR DATA ANALYSIS

#### Family Functioning

#### Adaptation

- 12. My household chores do not get done if I am unable to do them.
- 16. Our family would not ask for help from community agencies.
- 22. Our family is willing to accept help or assistance from friends.

#### Partnership

- 3. In my family we are not encouraged to express our opinions.
- 8. Our family does not have areas of common interest.
- 14. My family discusses problems such as allowances, clothing, and household responsibilities.
- 21. The amount of responsibility I have in our family is fairs.
- 23. Responsibility is not divided fairly among our family members.

#### Growth

- 4. Our family encourages each member to be independent.
- 6. My family accepts my wishes to take on new activities.
- 9. My family gets upset when I spend time away from home.
- 20. I accept it when other members of the family spend time doing things differently from the things I do.
- 24. Change within the family is not easy for me to deal with.

#### Affection

- 10. In my family we have difficulty expressing affection to each other.
- 11. I feel love for my family members.
- 13. Expression of anger is not easy for my family to accept.
- 17. My family responds to my feelings of love.
- 25. I feel my family cares what happens to me.

#### Resolve

- 2. My family spends time together for family activities.
- 5. Our family does not work well together toward a common goal.
- 15. Our family does not enjoy being together.
- 18. The amount of our family's money I am allowed for personal needs is fair.
- 26. The amount of space provided for my personal belongings is fair.

#### Compliance

#### Diet

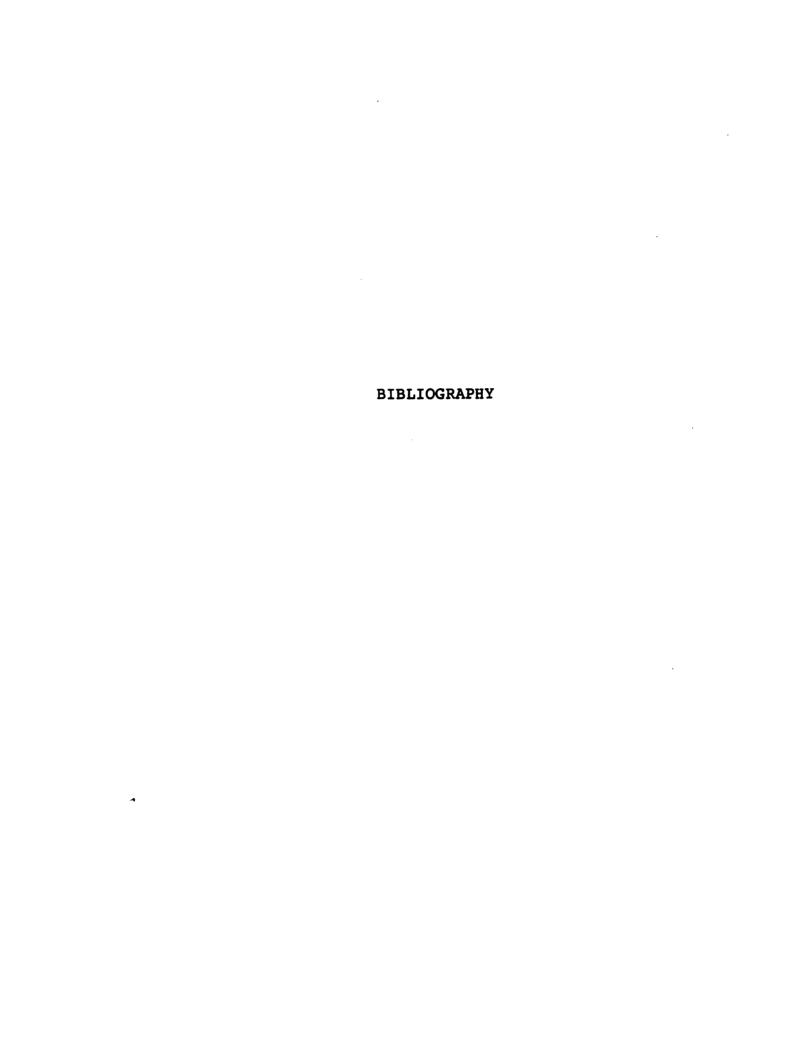
- 1. I have eaten snacks that are not on my diet.
- 3. I have eaten more than the number of calories ordered by the doctor.
- 4. I have tried to at least maintain my present weight.
- 6. I have eaten the foods I was told to avoid.
- 9. I have eaten only the amounts of food suggested on the diet ordered by the doctor.
- 12. I have followed my diet as ordered by the doctor.
- 15. Following my diet has interferred with my normal daily activities.

#### Medication

- I have been known to forget to take my medication.
- 5. I have taken my medicine in the amounts ordered.
- I have taken my medicine only when I have felt like I needed it.
- 10. I have gotton mixed up and have taken my medicine wrong.
- 11. I have forgotton to take my medicine when I have been away from.
- 13. I have watched for the negative (bad) effects of my medicine.
- 14. I have gotton my prescriptions refilled before or as soon as I have run out.

#### Follow-up Appointments

- 18. I have had my blood sugar checked whenever the doctor suggested I should.
- 19. I have not gone for my follow-up appointments when I have felt good.
- 20. I have reported reactions from my diabetic medication to the doctor.
- 21. I have kept my appointments to see the doctor or nurse.
- 22. I have avoided having my blood sugar drawn whenever possible.
- 23. I have gone to the doctor only when I have felt bad.
- 24. If something has occurred making it impossible for me to keep my appointment, I have rescheduled my appointment for as soon as possible.



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